



Club 13thirty: Christina DiBundo, Shannon Bronson, Lauren Spiker, Steve Esposito, Katie Lannon (missing Megan Scott)

13thirty Cancer Connect - Syracuse!

New doors open for AYAs!

Nineteen years ago, it was impossible to imagine how the lives of three extraordinary teens, each dying from cancer, would intersect, but on July 11, 2019, it became clear. We proudly opened the doors of our new Syracuse 13thirty Cancer Connect center in honor of Hannah Metzler, Charlie Poole, and of course, Melissa, the inspiration behind it all.

"It has always been our vision to expand to other communities," said Lauren Spiker, our Founder and Executive Director, "but how and when that would happen has been a work in progress."

The path to Syracuse started after Hannah, a beloved member of our group, died in 2014 and Lauren promised her parents that

we would use the generous gifts donated in Hannah's honor for our first expansion site. "We were thrilled that Hannah's legacy would help an organization that helped her and would continue to help many others," said Hannah's dad, Mike.

When we began supporting young adults as well as teens in 2015, opening a second location became a strategic priority. "The Rochester center had grown from a grassroots effort to an internationally respected organization and its benefits for teens and young adults were very clear," said Charlie Coté, Board President. "We were ready to do more."

So, when we met Charlie Poole, a teen from the Syracuse area, the wheels began turning.

— cont. on page 8

insights

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

Summer/Fall '19

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Save The Date!

Journeys, 18th Annual
Celebration of Living
Saturday, Nov. 2, 2019

13thirty

cancer connect

Teens and Young Adults

Get it Together!



Board of Directors

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A Message from Lauren Spiker Founder and Executive Director

Hello friends,

It's been a whirlwind ten months since we announced at Journeys last October that 13thirty Cancer Connect was expanding to Syracuse but I am proud to say, "We did it!" Though there was much to do and many pieces to fit into a puzzle that seemed to grow bigger each day, our Syracuse chapter is open and ready for business.

With the help of many who offered their time, talent and skill (see page 7 for all who helped), our new Center is as warm and inviting as our Rochester Center and almost twice as large. 13thirty Syracuse, conveniently located in Liverpool, NY right off Thruway Exit 37 and only 10 minutes from downtown Syracuse, boasts a full, modern kitchen for our nutrition classes, a large program room to hang out and connect with others, a cozy room for parents to share common experiences, and an awesome multi-purpose room for all our fitness programs and workshops.

Bringing our program to other communities has long been the vision but actually taking the step felt like a huge leap. If we build it, will they come? Will we be able to sustain a new operation? Can we replicate the same loving community that defines our Rochester 13thirty family? Each time doubt threatened to cloud our vision, I remembered a quote by Joel Barker that has helped me take many a first step into uncharted territory.

Vision is your dream in action.

Vision without action is merely a dream.

Action without vision just passes the time.

Vision with action can change the world.

Together, we can change the world for teens and young adults with cancer. With your help, we will continue to turn big, bold dreams into action. We promise to never just 'pass the time' because we know all too well how precious and fragile our time really is. And just like the movie, *Field of Dreams*, "If you believe the impossible, the incredible can come true."

Thank you for helping to make our dreams come true in such an incredible way,

Lauren

SAVE THE
DATE

JOURNEYS

18TH ANNUAL CELEBRATION OF LIVING

Saturday, November 2nd at 6:00 PM

Temple B'rith Kodesh

2131 Elmwood Ave. Rochester, NY

WINE PULL | SILENT AUCTION | RAFFLES
DINNER | COCKTAILS | AWARDS
PERFORMANCE BY 13THIRTY MEMBERS

NOV.
2

Check your mail in September or visit 13thirty.org

Chief Medical Advisors

Archie Bleyer, M.D.
St. Charles Medical Center, Bend, OR

David Korones, M.D.
Golisano Children's Hospital, Rochester, NY

O.J. Sahler, M.D.
Golisano Children's Hospital, Rochester, NY

Sue Ogle, MSN
Children's Hospital of Philadelphia, PA

Louis S. Constine, M.D.
Univ. of Rochester Med. Center, Rochester, NY

Staff & Other Awesome People

Lauren Spiker, Executive Director
Stephen Esposito, Program Director
Christina DiBaudo, ROC Events/Donor Relations
Shannon Bronson, ROC Digital Media
Katie Lannon, SYR Community Relations
Megan Scott, SYR Programs
Matthew Sengbusch, Tech. /Creative

insights

Lauren Spiker, Contributor
Stephen Esposito, Contributor
Christina DiBaudo, Contributor
Shannon Bronson, Contributor
Matthew Sengbusch, Designer

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.

13thirty Cancer Connect is a registered IRS 501 (c) (3) tax exempt organization. United Way donor choice agency #2383. Tax ID# 47-4493013

Awesome People - Club 13thirty!



Lauren Spiker - Founder and Executive Director

Lauren is our chief visionary with a pulse on what's happening in the world of AYA oncology. 13thirty began as a promise to her daughter, Melissa, and has grown to be an important place of connection, healing, and friendship for hundreds of teens, young adults, and families. Her dreams are big and bold!



Steve Esposito - Program Director

Steve brings a heart of gold and a collection of dad jokes everywhere he goes. Whether it's planning a crazy game night here at the Center, leading the charge for our fitness programs, helping to manage our Syracuse Center, or finishing off the last box of Girl Scout cookies, Steve's got you covered!



Christina DiBundo - ROC Special Events/Donor Relations Coord.

Raising funds, planning events, helping to grow our presence in Rochester, lending a hand - you name it, Christina's your girl! Bringing a smile and a love for all things philanthropic, you will most likely find Christina sipping a hot beverage and brainstorming the next big thing for 13thirty!



Shannon Bronson - ROC Digital Media/Community Relations Coord.

Like, Share, Comment! Shannon makes sure all our social media is up to date and on trend. She can be found with caffeine in her hand and Instagram on her screen! So whether you're looking at our posts or are at a Goin' Bald for Bucks event, Shannon is sure to be behind the scenes!



Katie Lannon - SYR Community Relations Coordinator

Having always dreamed of working for a non-profit, Katie found the perfect fit at 13thirty! You'll most likely find her listening to Spotify and drinking iced coffee while keeping up with the Syracuse community. Whether it's presenting at schools or planning unique events, Katie is ready for all things 13thirty in 'Cuse!



Megan Scott - SYR Program Leader

Megan brings enthusiasm to the new Syracuse Center and is eager to introduce new members! When she's not coming up with new and exciting programs, Megan likes to unwind through daily meditation. Come visit 13thirty Syracuse and she might have some homemade, gluten-free pastries to share!

SNAPSHOTS!

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

1. SLAMmin' Good Time

Our SLAM Poetry club has been getting together regularly to get their creative juices flowing! To hear more about it, check out our spotlight on Charlie Coté on page 11!



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2. Mother's Day Project

In May, some of our AYAs got together to make cookie mix in a jar as gifts for Mother's Day, and had a blast (as usual)!



3. Minute to Win It!

We had a wildly fun time playing "Minute to Win It" games with our teens and young adults! Players had just one minute to complete fun and silly challenges!



4. Rochester Police Department

RPD treated 13thirty to simulation exercises, shooting range time, and a tour of the training facility at the end of May. Pictured, Michelle shows her enthusiasm for the fun night. Thanks so much to RPD for all their support!

5. Cookin' Up a Storm

Once again, parents at 13thirty cooked a meal for the Ronald McDonald house! We had a great time giving back while making new friends (like Frankie, center.) A surprise visit from Isaiah all the way from N. Carolina was a special bonus!



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7



9



10



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6. On Your Mark, Get Set...

Go! This year's 7th Annual Bandana Bolt was the biggest one yet! We were so thankful for the beautiful weather, as well as so many good friends to share it with!

7. 13thirty Family Picnic

This year's annual family picnic was so much fun, connecting with friends and family old and new (and seeing so many of our grand-members), playing lots of giant Jenga, and eating delicious food!

8. Father's Day Cookout

In June, we celebrated our annual Father's Day cookout on the rooftop patio of the Al Sigl Community of Agencies! The night was filled with laughs as well as Steve's superb barbecue skills!

9. Radio Social

Giant Jenga has been the name of the game this summer! Our AYAs enjoyed a fun night out at Radio Social bowling and playing indoor lawn games!

10. I'm a Survivor!

Steve and a group of our members and their families attended the Wilmot Survivors Night at Frontier Field on August 9th. They were proud to join the on-field parade and proudly hold the American flag together. Everyone had a BALL!

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Celebrate &
Live Life
with Joy!



Our fearless leader addresses the crowd! Lauren gave a beautiful speech about 13thirty's history and our honorees, Hannah and Charlie.

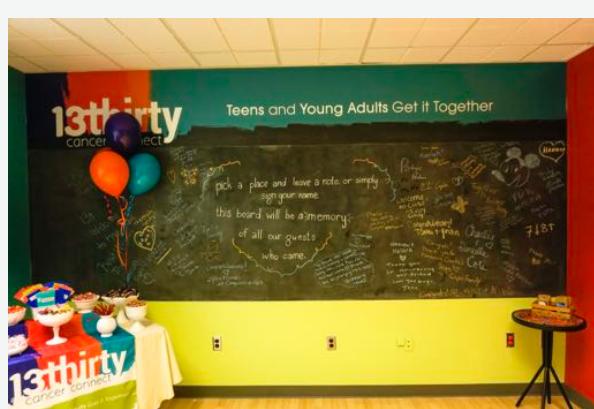
Grand



Open for business! The Metzler, Poole, and Spiker families cut the ribbon alongside Jack Sheridan (young adult survivor) from On My Team 16, to officially open 13thirty Syracuse!



Charlie's mom and friend in our brand new kitchen where Syracuse teens and young adults will have the chance to learn about nutrition and cooking skills!



Thanks a million! Our fitness room chalkboard wall invited attendees to leave notes of love, support, and gratitude.

We loved reading each and every one of them!

opening



Full house! We were thrilled to have so many friends, family, and supporters travel from far and wide to our Grand Opening.



The Grand Opening was a SWEET day, especially with our tasty candy table!

THANK YOU TO OUR 13THIRTY CHAMPIONS



Funders



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Sponsors



Hugs were abundant during the Grand Opening, the best way to celebrate!

Syracuse Grand Opening - cont. from page 1



Like Hannah, Charlie had been diagnosed with a rare brain tumor and given a dire prognosis. But the outgoing teen still had much to do including driving 95 miles from his home in Fayetteville to attend our programs. "I like that you have something to relate to everybody else in the group," Charlie later said after attending our programs. "It's nice to be able to get to know other people who understand the whole cancer situation, let it all out and connect."

He searched for resources like 13thirty Cancer Connect in his community but his search fell short. We needed to change that and began exploring expanding to Syracuse. Sadly, Charlie died in August 2018 but during our last visit, we promised that if we were able to bring 13thirty to Syracuse, it would be because of him. Again, generous gifts in honor of Charlie were directed to us and added to Hannah's.

A successful campaign provided necessary additional funds and by March, the walls of our newly leased space came tumbling down, soon to be rebuilt with the help of scores of generous 13thirty Champions. From architectural plans to drywall, plumbing, HVAC, electric, flooring, painting and everything in-between, we were blessed to have all of the work either donated or deeply discounted. Even most of the furniture and accessories were donated by friends. With every last detail complete, we cut the ribbon and welcomed over 100 people to our Grand Opening in July (more photos on page 6-7).

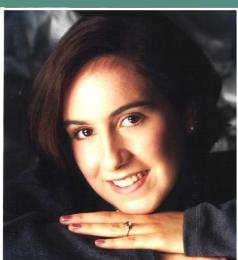
Thanks to many, Syracuse teens, young adults, and their families will now be able to connect with others who understand. Our brightly colored and comfortable center boasts a large program room for game nights, expressive arts, and 'hanging out' while our cozy parent's room provides space just for them. A full kitchen with a family-sized table will accommodate nutrition classes as well as space to gather in friendship. We are especially proud of our fitness room where a range of wellness programs will be offered including group exercise classes, yoga, massage, and opportunities for individual workouts.



If you're in the area, please stop in for a visit. Katie and Megan will love to give you a tour!

Three Teens. Three Promises Kept.

Though they never met, Melissa, Hannah, and Charlie were much alike showing unwavering determination and steadfast courage in the face of incredible adversity. Their legacies endure and their lives will inspire everyone who steps through our door to "make a difference, to make things better." Just like Melissa asked.



Melissa
1981-2000



Hannah
1996-2014



Charlie
2001 -2018

3rd Annual "Melissa's Legacy Circle" Garden Party

Melissa's last request of her mom - "to make a difference, to make things better" - is at the core of everything we do and Melissa's Legacy Circle recognizes those who have done just as Melissa asked - made a difference by donating \$500 or more in the previous year.

Before Melissa died, she made sure her parents knew what was important to her. She wanted those she loved to have a place where happy memories could be embraced and gentle breezes would remind them of her. Thus bloomed Melissa's Garden, the perfect place to thank our Legacy members.



The rain held off for a beautiful July evening in Melissa's Garden.

After crossing the arbor, guests were greeted with champagne and our signature butterfly pins. With flowers in full bloom, guests enjoyed delicious appetizers passed by our 13thirty members and Associate Board members, while admiring Doug and Lauren's beautiful gardens.

Anthony Siciliano of Head to the Roots set the mood with live, acoustic melodies. Lauren closed the evening with one of our beloved traditions, "An Ode to Good Friends", a heart-warming yet whimsical poem in which all Legacy Circle members are personally thanked.

The Garden Party is a special evening enjoyed by all who attend. We hope you will join us next year!

2019 LEGACY CIRCLE HONOREES

Anonymous Friends

Mike & Julie Allen

David & Jen Arnold

Drs. Dennis & Barbara Asselin

Patricia Bedard

Jared Bertoni

Gina Bianchi

James & Gina Blaeser

Joseph & Mary Calabrese

Jeffrey Carlton

Marilyn Cerame

James Connaughton

Dr. & Mrs. Sandy Constine

Charles Coté & Danielle Schied

Tony Cotroneo

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Daniel & Mary Duprey

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David Marsh & Barbara Carr

Scot & Julie McNair

Michael & Nancy Metzler

Erik Miller

Joe & Mary Beth Morelle

John & Lisa Nichols

Richard & Jean Ottalagana

Deborah Owlett

Tim Pellittiere & Kristin Jonsson

Stephanie Perotti

Douglas Pickard

Jim & Cheryl Pohlman

Tom & Priscilla Poole

Keith & Lynda Poole

Michael & Christine Russo

Rob Sailer & Susanne Nowatzki

David & Kathy Schlede

Elaine & Joseph Scuderi

John & Julie Sidou

Mark & Carol Simoni

Daniel & Erin Sirianni

Deborah Skarpness

Stan Spector & Paula Brown

Doug & Lauren Spiker

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Chris & Rosalie Stocks

Lindsey Sturdy

Steve & Aimee Synesael

Donald Tomeny

John & Hilda Violante

Dr. Kevin Walter

Ron & Lynn Ward

Joe & Adelita Wischmeyer

THANK YOU!

ALWAYS IN OUR HEARTS - Sabrina Elizabeth Gauer



August 12, 1988 - April 12, 2019

There are work groups and then, there are work groups. Club 13thirty, the name that Sabrina coined for our team, is one of the latter and it will always be missing a piece of its heart without her. Though we were able to share time and space with Sabrina for only a short time, it didn't take long to recognize her many gifts and talents, not only as our Communications Coordinator but as a special human being.

So many words describe Sabrina – singer, songwriter, believer, daughter, sister, friend, survivor. She wore many hats, some at the same time. Beautiful, witty, fearless, determined, brave, self-aware. These characteristics and more made Sabrina shine inside and out. Yet none of these words capture the full essence of who she was and will always be to those who loved her.

Words by themselves are inadequate but when coupled with memories, we remember Sabrina and smile through our tears. She showed us the true meaning of integrity, to act in accordance with one's beliefs and values. Every day, all the time, not just when convenient or when others agreed. Sabrina didn't just talk her talk. She walked her talk, difficult as it was, with uncommon dignity and courage. For that and so much more, she earned our respect. Her spirit was generous, her heart always open. Her laughter, contagious. She loved as easily as she was loved and we miss her.

You'll always be a part of of Club 13thirty, Sabrina. Fly high and well, sweet friend, and fill the heavens with song.

LIGHTHOUSE

Music and lyrics by Sabrina's friend, Jeff Carl*, written in honor of Sabrina and sung at her memorial service.

Did you have a deal with the sky
You picked a rainy day to die.
It's like you knew we'd need the rain
To wash the puddles all away
From all the tears we'd cry.

I hope they got your new house right
And that it's a color that you like
And that it's always summer.
When we were younger
You would always find the light
You always made it brighter.

You made it better.
You made it matter.
And you'll make it even better still
Even when we feel like
All the years we had weren't enough
You're still a lighthouse,
Always saving us.

Been tryin to find the reason why
Been tryin to make it all alright
And is it wrong of me to yell at god
For taking you away from us?
It's hard to see the bright side.
'Cause you made it better.
You made it matter.
And you'll make it even better still
Even when we feel like
All the years we had weren't enough
You're still a lighthouse,
Always saving us.



Spotlight On



Charlie Coté
Clinical Social Worker
13thirty Board President

Tell us a little about yourself.

I am a clinical social worker in private practice and the author of *I Play His Red Guitar* (Tiger Bark Press, 2019) and *Flying for the Window* (Finishing Line Press, 2008). I teach poetry at Writers & Books and serve on the board of 13thirty Cancer Connect, where I often volunteer as a creative writing wellness facilitator.

How did you get involved with 13thirty Cancer Connect?

My son Charlie met Lauren while undergoing treatment for melanoma. He began attending events, relieved to be among other teens who knew what it was like to live with cancer. I was impressed with the warmth of this community and the support we experienced.

What led to your becoming President of the 13thirty Board?

Lauren invited me on the board several years ago and I accepted immediately as the values, vision, and mission of the organization resonated with my own. As the needs of the organization began to grow, the board too needed to adapt, become more diversified with regards to perspectives and expertise. Because of my background, both professionally and personally, and because I was more than willing, and the board believed I'd be a good fit, I was selected as President.

What's a fun fact about you?

When I was a teen, I wanted to be a professional water skier and competed in slalom and jumping competitions. My other

"I want people to know that 13thirty is a place that's making a real difference."

interest would have been sky-diving but my mother said she'd disown me if I ever tried.

What is your favorite movie and book?

Amelie and Napoleon Dynamite are two favorite films because Charlie admired them so much. The former captures his romanticism and creativity, the latter his quirky sense of humor. My favorite book is *The Brothers Karamazov* by Dostoyevsky. It captures the human spirit in all its various forms, the light and dark of it all.

What are your goals for further expanding 13thirty?

I want to see 13thirty Centers in every city where teens and young adults are treated. My hope is to be an ambassador for our mission and vision by giving poetry readings and creative wellness workshops at cancer centers and bereavement groups around the country.

What would you like people to know about 13thirty?

13thirty Cancer Connect provides a place where teens and young adults can be themselves, where they can receive and give support, and live their very best lives. Our teens and young adults are vibrant, creative, fun, talented, and loving people. So are their family members, their friends, along with our staff and volunteers. I want people to know that 13thirty is a place that's making a real difference.

You are helping us "make a difference," Charlie!

Charlie "Opens the Door" to Poetry for 13thirty Members

We are excited to have Charlie working with our teens and young adults on a new program - Slam Poetry, or performed poetry. For several months, Charlie has led workshops on the theme of "doors" to help our members write about their cancer experience - the doors they've opened and the doors that have closed.

"What impresses me so much," Charlie says, "is how articulate our teens and young adults are about their experience, how willing they are to share openly, how passionate they are about their lives."

Charlie is the perfect person to lead this effort as he is a popular local poet who recently had a new book published.



I Play His Red Guitar can be purchased at tigerbarkpress.com.

I Play His Red Guitar is a collection of poems inspired by his son, Charlie, who died in 2005. The book's beautiful cover was designed by Charlie's daughter-in-law, Alison Coté.

Writer Sarah Frelich describes the collection as, "perfectly pitched poems circumscribing a narrative arc that starts in hope and fear, travels through pain and rage, and arrives finally at the sort of wisdom that is earned only after loss."

You can see our teens and young adults perform their Slam Poetry pieces at Journeys on November 2. Please come support them!

Thank you, Charlie, for sharing your time and talents with us!



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Rochester, NY 14620

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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!

\$100 \$75 \$50 \$25 Other _____

in honor of in memory of _____



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*

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YOUR SUPPORT WILL MATTER!