



13thirty - Syracuse members "Pour it all Out!"

Together, Friends Help Heal Hearts with Art

When Syracuse artist, Eva Hunter, met with Syracuse -13thirty members a few months ago, her Acrylic Pour class was more than just a painting class.

The technique of pouring acrylic paints onto a canvas and then swirling the paint to form undulating rivers of colors is an apt metaphor for our expressive arts programs. Sometimes, you just have to let it all pour out and see where it takes you.

All the peer support programs offered at 13thirty Cancer Connect are based on three pillars which, we believe, best help our teens and young adults live their very best lives.

Our wellness programs help them get stronger physically, and our just-for-fun social programs bring back a sense of

normalcy with friends who don't need explanations.

The third area of focus, expressive arts, offers creative time and space to process all they've gone through in ways unique to them. Art therapist, Aubrey Donovan, has worked with our members for many years.

"Creative arts therapies," she says, "offer participants immersive, restorative experiences that support overall well being, as they navigate the celebrations and challenges of life."

Using a variety of media, deep feelings and new perspectives, for which words are sometimes not easy, can be shared with friends who understand.

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insights

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

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On Your Mark! Get Ready!

10th Annual
Bandana Bolt 5K
& Team Relay

June 5, 2022



Teens and Young Adults
Get it Together!



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Thanks to Our Print Sponsors



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,

Have you ever had the experience of walking into someone else’s home and immediately feeling comfortable? As if you’ve known the place all your life? Or maybe, you remember having met someone for the very first time and instinctively saying to yourself, “We could be friends.”

If asked to explain, words may be hard to find. “I just felt it,” might be your only explanation. Well, some things are like that. You can’t see it, you can’t describe it. But you can feel it. In the book, “The Little Prince”, the main character, a traveler from a distant land, learns a very important lesson.

*It is only with the heart that one can see rightly;
what is essential is invisible to the eye.*

Antoine deSaint-Exupery

When you walk into our 13thirty Cancer Connect center, you experience the same phenomenon. It just feels good. Safe. Warm. You feel important and respected. You sense being cared about and cared for. It feels like home. Your heart knows.

Yes, the walls are colorful, the staff friendly, and the furniture comfy but it’s more than that. It’s something you can’t see or touch but you know it’s there. It’s the underpinning of everything we stand for and to which we hold ourselves and each other accountable—our values. It’s our values in action that set the course for everything we do and say. Please take a few minutes and acquaint yourself with our values (p.6). Should you ever feel we are not walking our talk, please let me know.

Today, more than ever, we must all heed the lesson of the Little Prince. May our hearts see rightly that which is essential.

With deep thanks as always,

Lauren




CNY Cancer Alliance

THE CNY CANCER ALLIANCE PRESENTS

SPRING INTO WELLNESS

A FREE community health fair for all residents of the greater Syracuse region



APRIL 30, 2022
9:00AM - 2:00PM
 1035 7TH N ST. LIVERPOOL, NY 13088
 WILL BE HELD OUTDOORS, RAIN OR SHINE
 PLEASE FOLLOW ALL REQUIRED COVID-19 PRECAUTIONS

<p style="text-align: center;">SCHEDULE A SCREENING!</p> <p style="text-align: center;">(appointment required)</p> <p style="text-align: center;">The Upstate Mobile Mammogram Van will be on-site! Call (315) 464-2582 upstate.edu/noexcuses</p>	<p style="text-align: center;">Support agencies from western and central NY will share information about the services each provides for cancer patients and caregivers.</p>	<p style="text-align: center;">SCHEDULE A DONATION!</p> <p style="text-align: center;">(appointment recommended)</p> <p style="text-align: center;">The American Red Cross Bloodmobile will be on-site! Call 1-800-REDCROSS redcrossblood.org Sponsor code: 13thirty</p>
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The Central New York Cancer Alliance is focused on centralizing available resources in order to increase access, improve education, and advocate for greater communication and support for those affected by cancer.

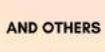











Welcome Clare McKenna!



Hello everyone!

My name is Clare, and I am the new Program Engagement Specialist here at 13thirty Cancer Connect! I first started with 13thirty in early February 2022 and have been loving life ever since!

I was born and raised in Rochester, NY where I grew up with three younger siblings. I played both soccer and lacrosse at Brighton High School and was then, and still am, a social butterfly - always wanting to be around friends and family and being active, especially outdoors!

I have had a passion for helping others for as long as I can remember, and have been very involved in my community from a young age. After graduating from SUNY Geneseo, I spent time trying to figure out where my psychology and human development degrees could overlap with my desire for a mission-driven career.

I've spent time working with multiple non-profit organizations in Rochester, working with teens experiencing mental health

crises, and working with cancer patients at the Dana Farber Cancer Institute in Boston. Through all of these incredible opportunities, I was able to clearly see the major impact that physical health can have on mental health, as well as the lack of accessibility to resources in these cases. I realized that this "gap" was the exact space that I wanted to fill.

When introduced to 13thirty Cancer Connect, I was inspired by their steadfast efforts to create a safe space for such an underserved population in the cancer community. Recognizing the unique struggles that adolescents and young adults with cancer face is the first step to providing services and resources that meet those specific needs.

I quickly decided that 13thirty was the place for me not just because of what they do, but who they are. The group that I work with is made up of the most passionate, generous, and fun-loving people that I have ever met. I can only hope to bring that type of energy to my role as the Program Engagement Specialist!

Welcome to Club 13thirty, Clare!

SNAPSHOTS!

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

1. Fall Festivities

Syracuse AYAs put their jack-o'-lantern making skills on display for a fun night of friendly competition! Always a great night with Amy!

2. Journeys Watch Parties

We loved seeing our 13thirty Champions and friends come together to view Journeys 2021 - virtually! Fingers crossed, we'll be in person this year - November 5th!

3. Glutesgiving Squad

Special thanks to Coach Mike, founder of the ROC Strong Club, for hosting the Glutesgiving Charity Workout event! Look for more fitness tips from Mike soon!

4. You're the Bomb Program

Syracuse AYAs created DIY bath bombs to give to the special people in their lives! Lucas and Connor were experts!

5. Welcome to the Club!

Rochester staff celebrated our newest addition, Clare, with a pizza night at Lauren's house! Wish the SYR crew could have joined us!



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6. **Painting A Masterpiece Program**
Nationally known, URMC artist-in-residence, Charmaine Wheatley, helped Rochester AYAs find their inner talent and voice. Thanks, Charmaine, for sharing your time and heart!



7. **First Come, First Serve!**
Our planning committee is working hard to create the #1 team tennis tournament in Rochester - the *13thirty Cancer Connect Cup* - June 11. Hope to see all our tennis friends there!



8. **Pour it Out Program**
Syracuse young adults tried out the trendy acrylic pour painting method with the help of local artist, Eva Hunter. Beautiful paintings were created by beautiful people!



9. **Giving Thanks - Together!**
Our traditional Friendsgiving dinner was extra special thanks to our friends at the Ryan Callahan Foundation who hosted the evening! Thanks, Kyla and Ryan!



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10. **Community Support**
We are grateful to the Marilyn Lichtman Foundation for a generous grant to support development of our new wellness app - *13thirty To Go!* Stay tuned for its launch in June '22!

Happy
Spring!

Healing Art - cont. from page 1

The old saying, 'it takes a village', is certainly true when it comes to our expressive arts programs, often led by area artists who generously share their time and talents.



Recently, our ROC AYA members experimented with water color crayons when Charmaine Wheatley, the artist in residence at Golisano Children's Hospital, spent an evening at the Rochester center.

"It was great to just be creative and see where it led," said Serena Dennis. With Charmaine's gentle coaching, members who were first unsure of their ability to paint, discovered the artist within, and were not only surprised but proud of the work they created.



Syracuse AYAs also reflected on their own winding, unpredictable experience using art as the medium. Like art, cancer is better understood when shared with others.

One expressive arts project, always months in the making, is the original presentation by our AYAs at *Journeys*, our *Annual Celebration of Living*. Those who have been to *Journeys* know how special this production is as they see and hear what it's like to be a teen or young adult with cancer - first hand!

Even though *Journeys* was virtual again due to COVID, our members created and performed an incredible, remote performance, choreographed by one of our AYAs, Kara

Skrubis, who was an 18 year-old college freshman when diagnosed with osteosarcoma in January 2020.

Dancing since the age of three, Kara aspired to a professional dancing career until cancer took her left leg. Despite the amputation and intense treatment during the pandemic, Kara was determined to dance again. And she met that challenge when she choreographed a dance piece for our members - all learned and filmed remotely!



Using movement, poetry, and music, Kara's piece, "Together We Rise!" describes the path our AYAs take when joining 13thirty. At first alone, they meet one, and then many, new friends. Before long, they are part of the warm, caring community that defines 13thirty Cancer Connect.

Kara led this amazing artistic effort, in collaboration with Charlie Coté, 13thirty parent and poet, and Dan Roach, sound designer, both of whom have lent their talents to many, many *Journeys* productions.



Art is the universal language. It speaks to each of us in our own way, in our own time, in our own space. Even knowing she was dying, Melissa found beauty and peace at the pottery wheel, continuing to live with purpose. What will you create?

Check out *Journeys 2021* and Kara's masterpiece on our [13thirty Cancer Connect Facebook page](#).

Values in Action - Walking the Talk!

At 13thirty Cancer Connect, our values are much more than just words in the employee handbook. They are the foundation of everything we do - for our adolescents and young adults, their families, our donors, and our community. We strive to incorporate our values into every program and each personal interaction.

TENDER LOVING CARE

Compassionately nurture each person's spirit with warmth and kindness.

RESPECT

Preserve the dignity of all by valuing each person's inherent worth, unique needs, and capacity for self-determination.

RELEVANCE

Provide meaningful resources congruent with mission and values by staying abreast of medical, social, and technological trends.

HONESTY

Engender trust by fostering open communication, being fair and truthful in all transactions, and adhering to the highest standards of professional integrity.

SAFETY

Create an environment where people gathering in friendship feel physically protected, emotionally safe, and psychologically unburdened.

STEWARDSHIP

Continually improve our business practices in order to manage our resources wisely and sustain the organization's mission.

Spotlight On



Dr. Jeffrey Andolina
 Director, Pediatric Bone Marrow Transplantation

University of Rochester Medical Center

"AYA patients are often caught between the pediatric and adult worlds and systems."

Describe your role and what you find most satisfying.

My clinical interests include leukemia, lymphoma, and bone marrow transplantation. I strive to be involved in clinical research, including local projects as well as opening up national trials in Rochester. The most satisfying part of my job is watching a child or young adult overcome a life threatening illness, and get back to a normal life.

What challenges do your AYA patients face?

These patients face incredible challenges, different from younger children and older adults. Many AYAs have major financial burdens, may not have insurance or a primary care physician, and may not have a family member to help. Compliance with medications and visits can also be an issue.

Mental health issues, as well as concerns over future fertility are usually very important. Finally, and maybe most importantly, until recently, there have not been dedicated treatment protocols or clinical trials aimed at AYAs specifically. All of these barriers can be significant, thus, the need for dedicated systems and supports to overcome them.

How is caring for AYAs different from other age groups?

Caring for AYAs is, without a doubt, more difficult than caring for younger children or older adults. AYA patients can be more difficult to physically get into clinic, or to reach by phone. I have found using technology to be very effective—many young adults would much prefer to text than to call.

In my experience, AYA patients do best when connected to a small number of medical team members, with whom they can develop trust. AYA patients may also not be forthcoming with symptoms or problems. While I have found that they are not dishonest directly, they will often omit important information unless directly asked! We try to involve multiple support teams, including social work, child life, community groups, and financial support.

What changes have you seen in the care of AYAs?

I have seen lots of changes for the better. There is now much more awareness of this population and more interest from the medical community on this age group. Nationally, there are many physician groups/conferences/conference calls related to how best to treat this population. Locally, we are lucky at URMC to have pediatric and adult oncologists under the same roof and same systems, and thus easily able to collaborate. There are multiple physicians on both sides here who are dedicated to this population.

When you're not hard at work, what do you enjoy doing?

When I am not at work, I am spending time with my family. I have a wife and five children – so home is often busier than work. I enjoy sports, and so I am often coaching or watching my own kids play sports. Being a parent puts life in perspective – certainly gives all of us additional reasons to do everything we can for our cancer patients and their families.

Thanks, Jeff, for recognizing and meeting the unique needs of our AYAs!



APRIL IS AYA CANCER AWARENESS MONTH!

Stay tuned! More events & collaborations will be listed at 13thirty.org

APRIL Return your bottles to Upstate Bottle Return to benefit 13thirty!	4/9 Charity Bootcamp Class at ROC Strong Club University of Rochester Women's Lacrosse Dedicated Game
APRIL Purchase our Healing Himalayan candle created by BeeKind!	4/13 Speaker Series: Passions In Action with The Butterfly Scar Project Fundraiser Night at Red Robin
APRIL Visit Upstate Vintage Market and round up your purchase!	4/24 Bodyweight Bootcamp & Flow Class with ROC Fit Collective
4/4 Strong Memorial is lighting up the hospital for AYA Month!	4/30 CNY Cancer Alliance: Spring Into Wellness Health Fair Sunset Yoga with Yoga+



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10TH ANNUAL
Bandana Bolt
5K & TEAM RELAY
SUNDAY, JUNE 5, 2022
#BANDANABOLT2022
REGISTER AT 13THIRTY.ORG

13THIRTY CANCER CONNECT CUP
Swing to support local teens & young adults with cancer at 13thirty Cancer Connect!
SATURDAY, JUNE 11 | 9-3PM | GENESEE VALLEY PARK

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**

Name: _____

Address: _____

City: _____ State _____ Zip _____

Phone: _____

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Please make your check payable to:

13thirty Cancer Connect
1000 Elmwood Avenue, Rochester NY 14620

or

Donate online at: 13thirty.org/donate

YOUR SUPPORT WILL MATTER!