



Teens & Young Adults - Cancer Can Not Mask Us!

"Behind every mask, there is a face and behind that, a story."

Each year at Journeys, our Annual Celebration of Living, we give our guests a glimpse of what it's like to be a teen or young adult with cancer through an original production directed by 13thirty members themselves.

The highlight of the evening is always an inspiring and thought-provoking performance, now a much-anticipated tradition. Planning for the next year's production begins right after the current one ends.

"We no sooner get everything put away and I start asking myself, What can we do next year?" laughs Lauren, our Executive Director.

Before long, a theme emerges and it's tossed around for consideration at the annual picnic in July. The conversation always starts with Lauren saying, "I've got an idea!" One idea leads to another, thoughts and feelings are exchanged and consensus is reached.

This year's theme was "Masks", something everyone could relate to. We all wear them - different masks with different people. Sometimes, different masks with the same person.

"Behind the mask, you stay strong and brave," said one young adult in the group. "You don't want people to know how you really feel. Sometimes, it's easier to just keep the mask on and fake it."
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insights

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

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SAVE THE DATE!

5th Annual Bandana Bolt
Sunday, July 9, 2017

**Kick Cancer
20K Race Series**

13thirty
cancer connect

Teens and Young Adults Get it Together!



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insights

Lauren Spiker, Contributor
Joshua Symer, Contributor
Stephen Esposito, 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 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 disease and treatment.

13thirty Cancer Connect is a registered IRS 501 (c) (3) tax exempt organization.
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A Message from Lauren Spiker Founder and Executive Director

Hello Friends,

As I write, the political landscape in our country is divided. During the long and rancorous campaign, it was the differences between us that captured the headlines and fueled the media and pundits. On lawn signs, in social media, and at dinner tables across our nation, opposing opinions about right and wrong, liberal or conservative policies and fundamental constitutional issues were debated. Most took sides, some publicly, some not.

In the end, votes were cast and a new President was elected. As we all knew would happen, the sun still rose in the east, the earth kept spinning on its axis and the republic remained standing. Because that's what we do. It's who we are. Somehow, what unites us becomes stronger than that which separates. Eventually, pretenses are dropped, promises take form, albeit not always as pledged, and goodness prevails.

So, what connection can be made between today's politics and our kids' cancer experience? In this issue, you'll read about a recent project through which our teens and young adults taught us all how to come face to face with reality and deal with it. To confront our fears and insecurities head on. To remove the masks behind which we often hide because it's easier and less painful than facing the truth.

At 13thirty, what we share in common overrides the differences. Masks are exchanged for fellowship. Real faces and feelings are revealed and respected. Today, I pray not only for our kids but for our nation to hold tight to that which binds us, one to the other. To honor our longstanding tradition of acceptance, compassion and shared vision.

For behind each of our faces lies a story, a deep-rooted story not always obvious but always worth listening to.

With hopes for the future,

Lauren Spiker

MARK YOUR CALENDARS!

Bandana
BOIT
5K Race & Fitness Walk

Sunday, July 9, 2017
Seneca Park,
Rochester NY

Part of the Kick Cancer 20K Race Series
Stay tuned for more information!



Saturday, May 20, 2017
Frontier Field
Rochester, NY

Volunteers Always Welcome!



A Film About Life with Purpose

When introduced to the award-winning documentary *Until 20*, we immediately knew we wanted to do something with it – but what? How could we use the film to heighten awareness of teen and young adult cancer?

After reflecting on the powerful message delivered by James Ragan, an amazing young man diagnosed at age 13 who lived until 20, we quickly decided to share it with the community.

Plans were put in place for the premier Rochester screening on September 15 at St. John Fisher College, a valued community supporter. With Rochester Regional Health, another partner, the event was accredited for continuing education credits for nurses.

Next, we compiled a distinguished panel for Q&A after the film to be moderated by Jennifer Johnson, a respected news anchor at 13WHAM News.

Nearly 300 community members packed Fisher's Cleary Auditorium to hear James' story. In his own words, the daily challenges faced by our teens and young adults were exposed and explored.

All of the most pressing issues that our kids experience were brought to the surface, including the impact on family, friends and healthcare providers as well as the difficult decisions at end of life.

James' moving story gives a face to adolescent and young adult cancer. Through his journey, people who haven't walked in his or his family's shoes are poignantly reminded about the meaning of living life fully.

Following the screening, we received valuable feedback from attendees expressing their desire to learn more about AYA oncology and how we are supporting this vulnerable group.

Moving forward, we plan to continue using this film to educate both school and medical communities about the unique needs of teens and young adults with cancer.

Thank you, James, for sharing your story and inspiring us all to live our very best lives!

Meet The Panelists



Lynda Beaupin, MD, Roswell Park Cancer Institute

Kristin Opett, RN, MSHA, Rochester Regional Health

David Korones, MD, Golisano Children's Hospital

Brittany McNair, AYA Survivor

Lauren Spiker, 13thirty Cancer Connect

"Is a good life measured by its length or its depth?"

This question, posed in the film *Until 20*, prompted many in attendance at the Rochester premier to ask the same question of others in their institutions.

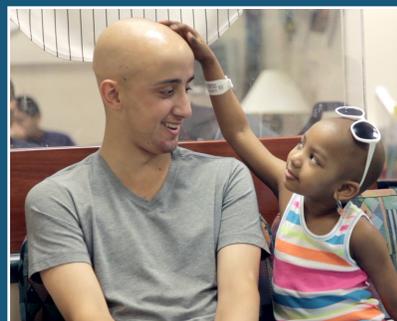
Jennifer Harris, Director of Elementary Education at Hobart & William Smith College, wanted her Human Growth and Development class to see the film and asked Lauren to facilitate the discussion.

"The students' reflections were amazing," Jen said. Many said the film changed their perspective on life.

UR School of Medicine, "Death and Dying in Modern Society" class, taught by Michael Brennan, FNP, also felt the film was relevant to them. Michael and twelve of his students, all future physicians, came to our Center to watch and discuss the film.

The film is one tool 13thirty will use to keep heightening awareness of AYA cancer. Another screening and panel is planned at Finger Lakes Community College this spring.

If you'd like us to bring this award-winning film to your group, please contact Lauren at (585) 563-6221



James Ragan and Krissy - *Until 20*

SNAPSHOTS!

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

1. Happy Birthday!

We celebrated our first birthday as 13thirty Cancer Connect in September! Friends and family stopped by for cake and to offer best wishes. The Symer's traveled from Myrtle Beach to start the festivities!

2. Halloween WalkAbout

The AI Sigl Community of Agencies hosted its annual "WalkAbout" at Eastview Mall and we were happy to lend our support! 13thirty handed out candy to the hundreds of amazing kids dressed up for Halloween!

3. Warrior Walk

Mark Bianchi, one of our young adults, helped lead the charge at the Wilmot Cancer Institute's Warrior Walk. Lauren was there with a congratulations hug!

4. Hilton Apple Fest

The rain and cold couldn't stop us from this year's Hilton Apple Fest. Michelle and other members of 13thirty's COR helped spread awareness of AYA cancer to our community all weekend.

5. Getting Educated

URMC School of Medicine students paid a visit to our Center for a private screening of *Until 20* and a follow-up discussion led by Lauren for their class, "Death & Dying in Modern Society."





6. Wine Pull

Once again, the wine pull at Journeys was a hit! A special thanks goes out to Matthew Phelps and Jessica Spector for making this a success.



7. S & S Bakery

Josh and Emily spent hours preparing hundreds of savory cookies that were enjoyed by all at Journeys. Hats off to them because these vegan chocolate chip wonders were a treat!



8. Props!

Board President, Charlie Coté, and his gang had a little fun with some props as they posed for pictures at this year's Journeys. Love the hair, Barb (third from left)!



9. Mr. & Mrs. Esposito

13thirty's Program Coordinator, Steve Esposito, and his now wife, Erica, got hitched! Their wedding happened to be on the same night as Journeys, so we let him off the hook this time. Congratulations!



10. Soul Pose

We had a great team volunteering at "Soul Pose" on November 12th. The blackout yoga event was put on by our friends from the Color Run. Always glad to help!



Want to increase awareness of AYA issues?

Invite us to present at your school, youth group and civic organization. You can help us make a difference!

Call us at:
585-563-6221

Masks article – cont. from page 1

With the general concept defined, the creative team was assembled to pull it all together.

- Charlie Coté led a writing workshop to identify the many masks worn during cancer and evoke the real feelings behind each one.
- Dan Roach interviewed and recorded members describing their experiences wearing their own masks.
- Lastly, Aubrey Donovan helped the group put faces to their masks – sketching, painting, and assembling.



The final product complete with a narrative script, slide show and larger-than-life masks was presented at Journeys on October 15.

Audience comments affirmed that chords were struck extending beyond our young people’s cancer experience. Haley Konzal, the mom of a young adult survivor, said, “Parents wear those masks, too, you know.” Other parents echoed Haley’s words.

Dr. Barbara Asselin, an attending physician at Golisano Children’s Hospital at Strong, commented, “The presentation was very moving and so relevant.” She asked if a video could be made to show other audiences. “It says so much. It teaches so much.”

Mission accomplished. Once again, our teens and young adults scored a hit and helped highlight not only their challenges but the magic that happens at 13thirty Cancer Connect.

Cancer is scary. It’s complicated and confusing. Often maddening and always frustrating.

Wearing a mask is often a way for our young people to deal with their own situation and emotions while also trying to protect those they love.



Mask creations (from top left, clockwise) Grin and Bear It, The Joker, The Cancer Card, All Put Together, Angry, Happy No Worries.



“The mask I wear the most is the All Put Together mask, especially for my mom. I don’t want her to see me struggle because I know it just breaks her heart,” said Cat.

But at 13thirty, masks are dropped at the door. They’re not necessary. Here everyone can just be themselves. No hiding, no disguises, no pretense. It’s OK, because at 13thirty we all understand. It’s safe to show our real faces and share our true stories.

Our name is 13thirty Cancer Connect. Cancer can’t mask us!

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2. Click Sign In/Create account in the top right corner
3. Fill in your contact information and submit
4. Start shopping and enjoy cash back while also making a difference for teens and young adults with cancer!

Pro Tip: Install the “Shop Buddy” Widget to save on every website where you shop!



Spotlight On



Tom O'Connor, President
Al Sigl Community
of Agencies

"Lauren has created an important and necessary family support agency and I'm grateful that it exists at Al Sigl."

We talked with Tom O'Connor, new President of Al Sigl Community of Agencies, where 13thirty ROC calls home!

Q: What path brought you to your new position as President of Sigl?

I was hired as the Marketing Director in 2008. In 2012, I became VP of Operations and when Dan Meyers, former President, announced his retirement last year, I entered my candidacy with the Search Committee and was fortunate to be selected to fill the role in June.

Q: What is the Al Sigl Community of Agencies?

Al Sigl is a collaborative network of community service organizations with 6 Member Agencies, 2 Affiliates, and 17 "Neighbors", as we like to call our tenant agencies. Al Sigl Foundation funds help support our Member Agencies and maintain our campuses and infrastructure. We also provide real estate and property management offering non-profits below market rental rates, shared communal spaces, and enhanced collaborative opportunities.

Q: How would you describe 13thirty Cancer Connect?

13thirty is a terrific organization. I've learned that many young people with cancer and their families often don't know where to turn for support. Lauren has created an important and necessary family support agency and I'm grateful that it exists at Al Sigl.

Q: How have you viewed the growth of 13thirty over the years?

13thirty, or Melissa's Living Legacy back in 2009, was one of the first, if not the first, organization not specifically helping people with disabilities to lease space here. We had redefined our mission to include special needs as part of our expansion. Your growth has been both strategic and measured, with the hospital partnerships being very important. 13thirty has also grown in terms of space, and for your audience, you guys have the absolute coolest space in any of our buildings. There's a reason we show off your headquarters on tours!

Q: What are your plans for supporting the neighbor organizations?

We're making a big push toward modernizing our facilities by investing in increasing energy efficiency, improving IT and communications, enhancing way-finding, and creating safer and more inviting spaces on our campuses.

Q: What is your vision for non-profits moving forward?

Greater collaboration. We have many organizations that do great work in their niche and often there is overlap which can better leverage resources and accomplish large-scale initiatives by working together.

*Thanks, Tom, for your support.
We love being your "Neighbor!"*

At A Caring Place, one of the bereavement programs offered at Lifetime Care, we believe that no one should have to grieve alone - especially our children!

Offered to children and teens coping with the loss of a significant person in their lives, A Caring Place provides a caring environment where their grief can be addressed with peers and trained professionals.

The program was created to provide families a safe place to come together and receive support and comfort in their grief while learning effective ways of coping with their feelings.



Grief can be a lonely experience for children and teens who may be reluctant to share their feelings. We help children and teens foster connections with peers who "get it," while respecting the uniqueness of each person's own grief experience.

This supportive environment helps children and teens feel validated, reassured and less isolated as they adjust to their experiences of loss and change.

For more information about A Caring Place, or our next 8-week group session, please contact us at 585-475-8800.

Alyssa Gupton, LCSW
Coordinator, A Caring Place & Assistant Director,



1000 Elmwood Avenue Door 9
Rochester, NY 14620

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13thirty Cancer Connect Wish List

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| Postage Stamps | #10 White Envelopes |
| Tissues | Printer Toner for HP LaserJet Pro |
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I wish to help teens and young adults with cancer live their very best lives...TODAY!

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in honor of in memory of _____

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**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**

Please make your check payable to:
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