



Paige and Will with baby Hannah!

# insights

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

## Family Planning Challenges for AYAs

**Never losing hope is one survivor's key to becoming a mother.**

When the phone rang at 11:00 PM and they saw it was their adoption agency calling, Paige and Will Strassner held their breaths. Could this be the call that would fulfill their fondest dreams?

"A brave and selfless young woman had chosen us to be the forever family of her child born that day," said a joyful Paige. After two years of unsuccessful IVF treatments and months of waiting patiently, Paige and Will were finally parents of a beautiful baby girl, Hannah Grace.

Paige and Will's quest to start a family mirrors that of many AYA couples who are unable to conceive a child naturally due to cancer and the effects of treatment.

Their story began when Paige was diagnosed with acute myeloid leukemia (AML) at 18 years old. As a senior in high school, Paige hadn't given a lot of thought to family planning.

But even if that were something she was ready to address, there wasn't time. A 2-6 week delay in treatment is generally necessary for fertility preservation procedures for girls. Because her cancer was very aggressive, Paige was urged to start treatment immediately.

"I started chemotherapy 12 hours after being diagnosed," remembers Paige. A bone marrow transplant was scheduled for soon after that. Thankfully, Paige survived and didn't think too much about having a baby until she met Will.

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## JOIN US!

Journeys, 17th Annual  
Celebration of Living

Saturday, Oct. 13, 2018

6 pm - 10 pm

**13thirty**  
cancer connect

Teens and Young Adults  
Get it Together!



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### insights

Lauren Spiker, Contributor  
Sabrina Gauer, Contributor  
Christina DiBaudo, Contributor  
Steve Esposito, Contributor  
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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.

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



## A Message from Lauren Spiker Founder and Executive Director

Hello Friends,

For most of us, there is a defining period during which our fundamental values are solidified and incorporated into our eventual path in life. For me, it was the tumultuous 1960's and '70's when universal themes about life and the human condition were being challenged by a rebellious counter culture.

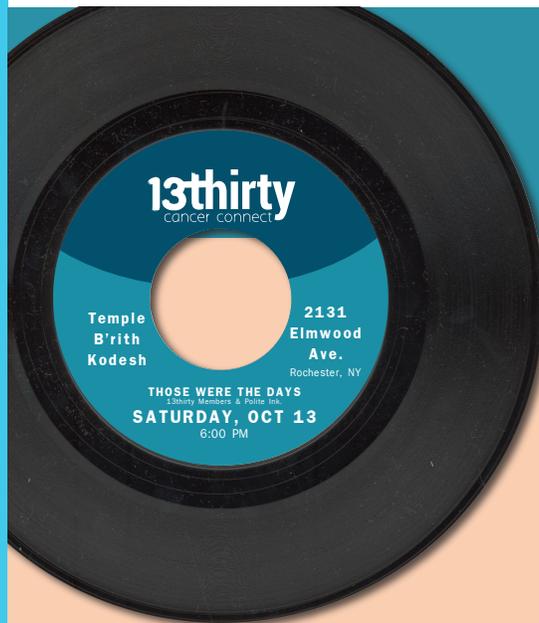
"The Prophet", the seminal work of poet Kahlil Gibran, originally published in 1923, had a resurgence of popularity during this period. For many, including myself, Gibran's simple, non-dogmatic parables shed light on some important life questions: love and marriage, war and peace, life and death, among others. When Melissa died and I began my work in support of other teens like her, his words on joy and sorrow assumed greater significance.

*"The deeper that sorrow carves into your being, the more joy it can contain."*

I've been reminded of these words the past month at 13thirty Cancer Connect when we experienced both deep sorrow at the death of our friend, Charlie, and the greatest of joy when our long-time 13thirty member, Paige and her husband Will, brought home their beautiful, adopted daughter Hannah Grace. I hope you will enjoy reading about them in this issue and be inspired.

I'm often asked, "Doesn't it make you even sadder when one of your 'kids' dies?" The answer is a resounding "Yes." But when one of my 'kids' does well and goes on to live fully and with purpose, the joy is immeasurable. And so we carry on, buoyed by the joy and fortified by the sorrow, remembering always that life is precious. That each day is a new chance to "make a difference, to make things better"- just as Melissa asked.

With deep thanks as always,  
Lauren



# Journeys

17th Annual  
Celebration of Living

COME LAUGH WITH US!  
RSVP NOW! - 13thirty.org

"Life is a tragedy when seen in close-up but a comedy in long-shot. To truly laugh, you must be able to take your pain and play with it."

- Charlie Chaplin



**On July 8th, over 120 runners, volunteers & supporters came out to Seneca Park for the 6th Annual**

**Bandana Bolt**

Our volunteers rock!

Doug's butterfly display for our handmade medals.

Runners + walkers of all ages joined us!

Signs on the 5K course remind us why we are here.

Team t-shirts + tailgating after the race!

Commemorative bandana artwork by Mark Sengbusch.

Remote runners joined the fun from afar!

**THANK YOU!  
See you next year!**

## You Don't Want to Miss It - Journeys 2018!

Journeys, our Annual Celebration of Living, is a special evening when we honor all the teens and young adults who have found friendship and support at 13thirty Cancer Connect.

We celebrate them and their families who become part of our bigger 13thirty family!

The highlight of the night is always an original presentation by 13thirty members that give our guests a realistic look at what it's like to be a young person with cancer.

This year, we're taking a humorous look back at the shared experiences that everyone at 13thirty understands.

Experiences that, in hindsight, can be laughed at but illustrate the difficult and unique challenges facing teens



and young adults with cancer. We are very excited to have the talented and hilarious sketch and improv comedy group, Polite Ink. working with us this year!

Polite Ink. specializes in both sketch and improvised comedy, performing their own sketches and improv games - on the spot - with audience input. Dancing, singing, and non-stop laughing are all part of the fun.

Polite Ink. and our 13thirty cast members are preparing a great show!

**Register now!**

**You don't want to miss this year's Journeys!  
13thirty.org**

Check out these funny folks at [www.politeink.com](http://www.politeink.com)

# SNAPSHOTS!

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

## 1. 2018 Bandana Bolt

It was our best year yet at Seneca Park! So many new faces and old friends alike ran and walked their way across the finish line for teens and young adults with cancer!



## 2. Annual Family Picnic

All smiles at the Spiker's residence! We love gathering every year to reunite with friends to share a meal and enjoy an afternoon of fun!



## 3. Golf Tournament

Several of our board members and good friends spent the day at Webster East Golf Club participating in the 8th Annual Flower City Invitational, hosted by Mike & Jen Zaffuts!



## 4. Melissa's Legacy Circle

It was a beautiful summer evening for the 2nd Annual Melissa's Legacy Circle garden party where we honor friends of 13thirty Cancer Connect who generously donate \$500 or more annually.



## 5. Wedding Bells!

Lauren was honored to attend the wedding of 13thirty member Quin Nichols and his bride, Nicole! While cancer bring us together, we also share some of life's wonderful moments with our teens and young adults!





6. Survivors Night at the Ballpark  
We enjoyed gathering together to catch a Rochester Red Wings game and celebrate survivorship at the annual Wilmot Survivors Night at Frontier Field!



7. Park Ave Fest!  
Lauren and Steve debuted our brand new 13thirty tent at the annual Park Ave Fest!



8. Birds for Charlie  
One of these sweet 13thirty birds (painted by Steve!) was buried with our friend, Charlie, who loved watching the birds from his window. The other was a small token of our love for his mom, Lynda. See more about Charlie on page 6.



9. Spirit of Life Award  
Congratulations to Alex Vogelwede, recipient of the 2018 Brittany Arnold Spirit of Life Award! This \$2,000 scholarship, supported by our friend, Jeff Carlton, recognizes a dedicated 13thirty member enrolled in an undergraduate college degree program. We can't wait to see your future unfold at St. John Fisher College, Alex!



10. Bald for Bucks  
Back-to-school means Bald for Bucks is back in session! Shoutout to Corey James and the 98PXY crew for supporting 13thirty Cancer Connect and Goin' Bald for Bucks!



*Happy  
Autumn!*

## Family Planning for AYAs - cont. from page 1

After Paige finished treatment, she knew that family planning would be an issue she'd have to deal with one day but for a long time, she kept it "buried away" and life went on.

She attended college for a degree in nursing and began working in the same hospital where she had been treated. When she and Will became serious, they talked about what would lie ahead if they decided to start a family.

"We both knew we wanted a family," says Paige. "I'd always planned on being a Mom."

When they were ready, Paige and Will opted for in vitro fertilization (IVF) treatments to see if Paige could get pregnant with a donor egg and Will could biologically father a child.

"It was hard," Paige told us, "both physically and emotionally. There were medications and injections to administer at home and it felt like we were on a constant rollercoaster." The steep financial costs added to the stress.

After two unsuccessful attempts, hearing that she wasn't pregnant was devastating. The couple had already decided that if IVF didn't work, they would pursue adoption but they needed some time. Time for Paige to grieve the lost opportunity to carry and give birth to a child and for Will, the chance to have a biological child.

"There were definitely some really hard days and weeks," remembers Paige. But being open with each other, their family and friends helped ease the pain.

"It was a time of growth for both of us," says Paige. "I think it also opened up a lot of people's eyes to the real struggle faced by so many others like us."

Determined to have a family and strengthened by their faith and love for each other, Paige and Will made their next family planning decision - to start the process of adoption.

Paperwork, home visits, classes, and nine months of waiting did not deter Paige and Will, but expenses continued to add up.

Ever resourceful, they turned to social media and started their own bottle and can fundraiser. "We set up an account at a local redemption center where they gave us \$.06 for every bottle!"

Friends, family and coworkers gladly started saving their bottles for Paige and Will to pick up. "It was smelly and often unsafe," laughed Paige, "driving with a car full of huge bags blocking the window."

Through it all, they knew that one day, they'd be able to bring in a picture of their little one and express their thanks. Now they can!

*Welcome to our 13thirty Family, beautiful, sweet Hannah Grace!*



To learn more about Paige and Will's story, visit our YouTube channel!  
[www.youtube.com/teenswithcancer](http://www.youtube.com/teenswithcancer)



## "To live in Hearts that Love is Not to Die"

We smile through our tears as we remember our friend Charlie Poole who died on August 6, 2018. Charlie found a missing link at 13thirty Cancer Connect - friends who understood. Though our Center is 95 miles from his home in Fayetteville, NY, he and his mom drove to Rochester whenever he was able.

Charlie was one of those people who lit up the room. The first time you met him, he just warmed your spirit and you felt better for having crossed his path. Charlie was a fierce advocate for other teens and young adults with cancer, especially others who suffered from the same, rare brain tumor - DIPG (Diffuse Intrinsic Pontine Glioma).

With the support of his parents, he unselfishly donated his brain for DIPG research at the Monje Lab at Stanford University. Always true to himself, Charlie opted for a green burial because of his love of nature and concern for the environment. Though we will miss his smile and quirky sense of humor, he will always be part of our 13thirty Cancer Connect family. We'll never forget you, Charlie!



Dan Roach  
Audio & Light Engineer

**"Their stories give others strength; 13thirty gives people hope and joy!"**

**Dan Roach has created magic at Journeys for several years now! Here's more about "the man behind the curtain."**

**Tell us a bit about you!**

I've studied music production, web design, and have been a professional sound designer for 30 years. I'm good at fitting music to the emotion of a scene or piece. I've had the opportunity to work with many actors, playwrights, and directors over the course of my career and I've even been known to compose music for various occasions. You may have seen some of my work at Geva Theatre, SUNY Brockport, or NTID.

*Fun fact:* I once played the National Anthem in six-part harmony with other tuba players at the opening of a Bills-Patriots game in Foxboro in the 1980's!

**What brought you to 13thirty? What about 13thirty resonates with you?**

I got involved in 2009 when PUSH Physical Theatre asked me to meet Lauren and help with Journeys that year. I listened intently to what 13thirty was about and realized if I could help people understand how resilient and wonderful the kids were, then that was something I wanted to be a part of. Their stories give others strength; 13thirty gives people hope and joy.

**Tell us about the personal impact of Journeys.**

I look at life through a different lens. I see young people facing huge challenges with honesty, grace, and humor in ways that

are truly inspiring. It's hard to describe how honored I feel that someone can talk about the most challenging moments in their life and include you in that discussion. If young people can cope with such life-altering issues, what is there for me to worry about? What can I learn from them for a time I am someday challenged in a similar way? I support them, but they support me as well.

**Do you have a favorite memory from your work here at 13thirty Cancer Connect?**

That first year is one of my fondest memories. We had many rehearsals and I individually interviewed everyone. I began to understand the incredible journey each person had to navigate with family, friends, and so many unknowns. They are all unique and special.

I remember interviewing one teen over the course of a 30-minute session. She cried several times during the interview and said it was the first time she had cried since her diagnosis. Her mom came up to me later and thanked me for listening and allowing her to express herself. I felt so privileged that people could invite me, a relative stranger, into their world and speak of things so weighty and personal. That connection is so strong, I still feel a real bond. It's like a family.

**Thank you, Dan, for helping make Journeys so special each year.**

**We are proud to honor you this year with our "Make a Difference Award."**

**THANK YOU TO OUR 2018 JOURNEYS SPONSORS!**

*Leaders*



*Believers*



*Dreamers*





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Looking for a fun way to support 13thirty Cancer Connect?  
Donate wine, a raffle basket or silent auction item for



*Journeys, the 17th Annual Celebration of Living*  
SATURDAY, OCTOBER 13, 2018

Get creative! Ideas include:  
art, crafts, electronics, experience tickets,  
getaways, gift certificates, home goods, sports  
memorabilia, themed baskets, toys, wine & more!

\* Your support for our wine pull, basket  
raffle or silent auction will directly  
benefit teens and young adults with  
cancer in our community.  
*You can make a difference!*



Call/email (585)563-6221 or christina@13thirty.org to make a contribution and arrange a pick-up.  
*Thank you!*

13thirty Cancer Connect is a non-profit, public benefit, charitable organization determined by the IRS to be a 501 (c) (3) organization in which goods are tax-deductible. Tax ID #47-4493013

## 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!

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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

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**YOUR SUPPORT WILL MATTER!**