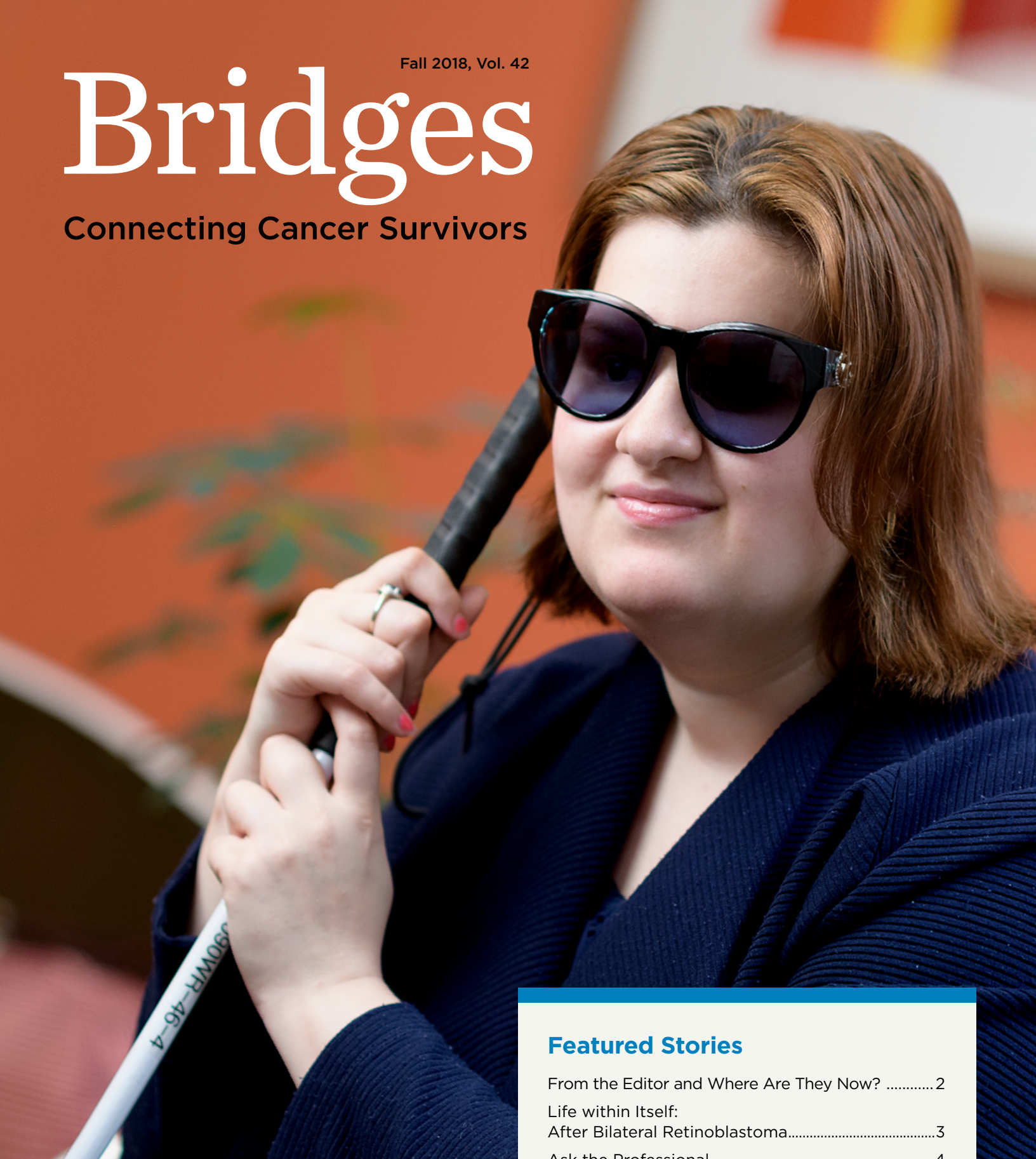


Fall 2018, Vol. 42

# Bridges

Connecting Cancer Survivors



## Featured Stories

From the Editor and Where Are They Now? .....	2
Life within Itself: After Bilateral Retinoblastoma.....	3
Ask the Professional .....	4
A Mother's Prayer .....	5
Resource Review .....	6
Cycling for a Cause .....	7



Memorial Sloan Kettering  
Cancer Center



## From the Editor

By Eileen F. Gould



On June 19, MSK held its annual Survivorship Celebration. The evening featured two engaging patient speakers: Carl Granum and Luisa Lyons. The keynote speaker was Ethan Zohn, a former professional soccer player, the winner of *Survivor: Africa*, and a cancer survivor. All three speakers were outstanding while sharing their very personal journeys. Following the speakers, there were information sessions on nutrition for people with cancer and the benefits of integrative medicine. Nearly 450 people attended the event. It is always

astounding to see so many survivors celebrating in one room.

That same month, *Bridges* celebrated its tenth anniversary — an amazing milestone. We look forward to sharing many more stories of hope and survival with our nearly 3,600 subscribers.

If you would like to submit your story or receive the electronic version of the newsletter, contact us at [www.mskcc.org/bridges](http://www.mskcc.org/bridges).



Bridges Exhibition Booth



Survivorship Celebration speakers Luisa Lyons (center), Carl Granum (second from left), and Ethan Zohn with MSK President Craig Thompson (right) and Adult Survivorship Program Director Stacie Corcoran

## Where Are They Now?

By Erin Chack

Erin Chack was a teenager when she was diagnosed with Hodgkin lymphoma in 2009. Since then, she graduated from Boston University with a degree in journalism that she uses as scratch paper at her blogging job. With more than a thousand posts and hundreds of millions of views of her writing under her belt, she's excited about where her career in distilling the weirdest parts of the

internet will take her next. In 2017, she published a book of essays in which she meditates on how easily cancer can un-normal everything. It sold a lot of copies, to her mom specifically. She often thinks fondly of MSK — the doctors, the nurses, and the very good French fries in the cafeteria. She is forever grateful to all of them (including the fries).



# Life within Itself: After Bilateral Retinoblastoma

By Selma Sulejman

I've learned there is not enough symbolism to explain all the emotions and experiences within the cancer and blind communities. What does exist is the reality of what one must face despite life's curveballs, the indefinite hardships that shape us as we determine how and where we'd like to go in our destiny.

As a survivor, I learned the ins and outs of advocating for myself in my postcancer life and as a young blind woman.

When my mother was still enjoying her new bundle of joy, I developed an elevated fever and an odd glow in my right eye. She rushed me to the hospital, where the two most beloved ladies in my life, my mother and sister, were told that I had cancer — retinoblastoma (RB). I had an emergency surgery, radiation, and cryotherapy, which uses extreme cold temperatures to treat cancer, all to kill the monster that had taken over my little body. Before I reached age seven, it became bilateral RB, and doctors at MSK deemed me completely blind just at the start of third grade. I think I speak for a lot of people when I say that both pediatric cancer and blindness can be placed within the group of debilitating circumstances in life.

As a survivor, I learned the ins and outs of advocating for myself in my postcancer life and as a young blind woman. Has it been a walk in the park? Absolutely not! I'm often identified as the blind girl—cancer survivor rather than the scholar I am. I've had to scream at people to be heard; to seek someone to truly listen and understand my personal frustrations in life due to cancer survivorship and blindness; to strive to prove to the majority that even though I am dealing with difficulty, I can still do things that an average person can, just within a different context; and to endlessly fight for equality. It is certainly not smooth sailing, but every marathon is worth running if one can make a difference for all people who are impacted by cancer and blindness.

As a young, disabled Islamic woman who is a bilateral RB survivor, I want to tell my fellow cancer survivors — my fellow fighters — and the blind community that although sometimes it feels like you are fighting battles alone and giving your all, you are not alone! Many of us are going through the same experiences, and hope is the key we must all hold on to.

I have days when I cannot get up due to low energy, times when every bone in my 29-year-old body aches and makes me gasp for my breath. And then there



Selma Sulejman is a 29-year-old pediatric cancer survivor who embodies serenity, enthusiasm, love, motivation, assertiveness, and empathy. She is unique and luminous, a Muslim and an advocate, and a pursuer of education and justice, and lastly, she is noble.

are the judgements I face from people when I am labeled as fragile. I fail to stay up late like many other people my age, and simply, I am different. Despite it all, I became an accomplished academic, learned how to take care of myself, advocated for my needs, and am figuring out how I would like to assist and change the world despite my undesirable disabilities.

To my dearest blind community, do not let anyone deter you from your dreams or convince you that you are less than the rest of the world because of bodily imperfections. It is these imperfections, such as cancer and blindness, that can lead you to leadership, peace, academia, unity, humanitarianism, and most importantly, love. Just keep your head up high and always continue to smile!

Imperfection is beautiful.

## Ask the Professional:

# Post-Traumatic Stress Disorder

By Matthew Doolittle, MD; Katherine Duhamel, PhD; and Jeannie Otero

### What is PTSD?

Post-traumatic stress disorder (PTSD) is the ongoing response to an episode of real or threatened physical harm or death. It is often related to injuries or abuse but can be caused by a diagnosis of cancer or another life-threatening illness.

Immediately after such an event, many if not most people may become more worried, have more anxiety, have trouble sleeping, or need to avoid anything that reminds them of the trauma. A few people may go through periods when they are inattentive or absent from what is going on around them. This is called dissociation.

Most of the time, the symptoms fade within a month or so. For some people, especially if they have had

a trauma before, the symptoms can continue. People may reexperience traumatic events as nightmares or flashbacks during the day. They may be irritable, angry, or anxious. They may startle easily or be sensitive to loud noises. They may need to avoid any stimuli related to the event or the environment where it occurred. They may feel as though they are at fault or that the entire world is unsafe.

### When does someone with cancer need treatment for PTSD?

People with cancer may be exposed to stimuli that produce trauma-related symptoms. Imaging machines, needles, and other parts of treatment may bring on these responses. Follow-up appointments and cancer-related

anniversaries can cause symptoms to come up again. These reactions can be limiting and distressing. People may avoid activities or appointments. If the symptoms last after the time leading to a scan or anniversary, or continue long after a traumatic event, treatment for PTSD may help.

### What is the treatment, and what is the prognosis?

Only a minority of people need treatment for PTSD. For most, the symptoms can be managed. PTSD almost always gets better with time. These reactions do not have to limit life after cancer.

Treatment can make recovery more efficient. Sertraline and paroxetine are the only two drugs specifically approved for PTSD. They are serotonin reuptake-inhibiting antidepressants. Other medications can help with certain symptoms, such as trouble sleeping soundly or nightmares. Identifying related conditions, such as depression or an anxiety disorder, is also important.

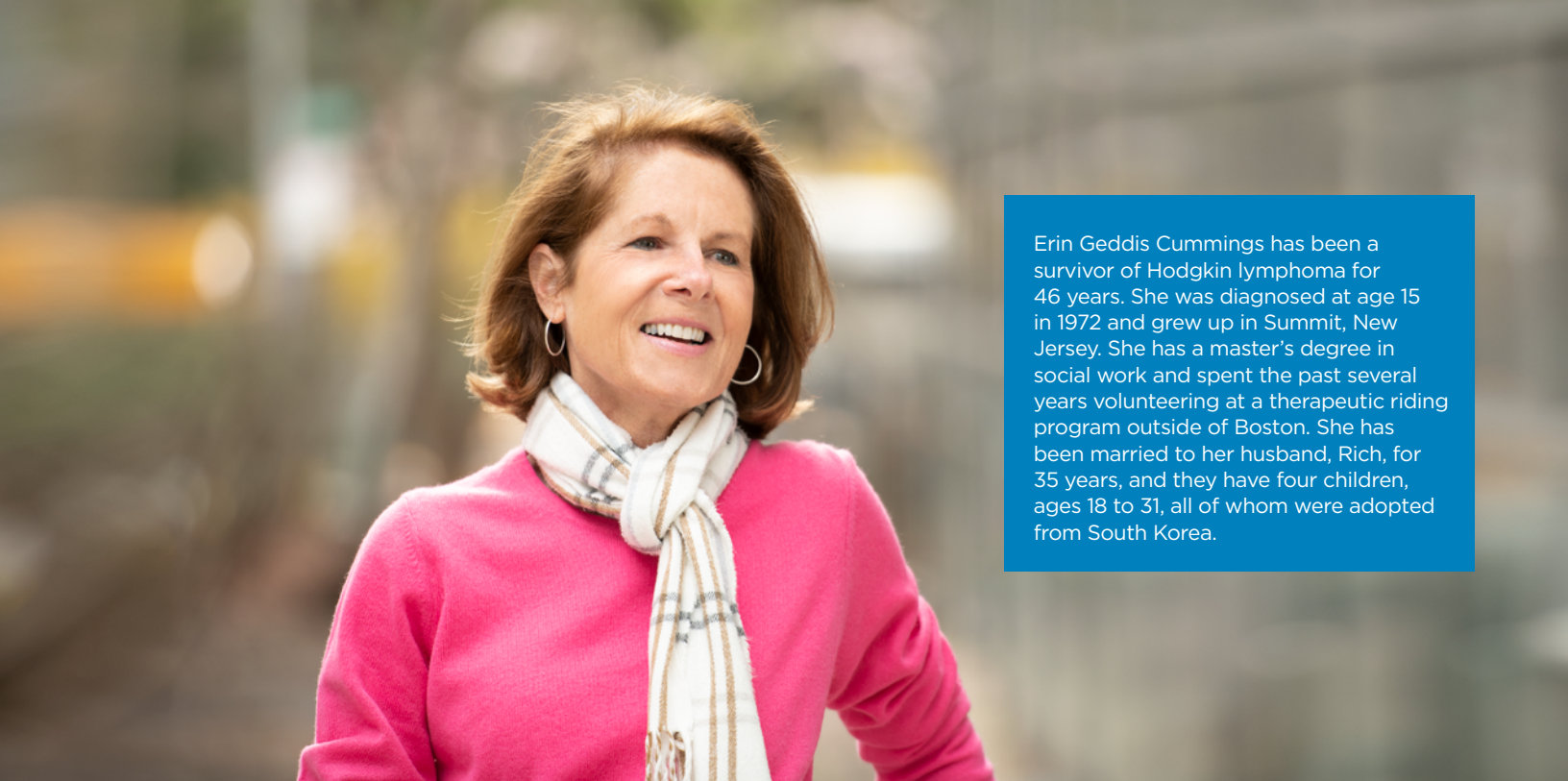
The primary treatment for PTSD is psychotherapy. Through therapy, people identify how the traumatic event is triggered. They can then work to stop that process. They learn to question their thoughts and emotional responses to a trigger.

The important thing to remember is that once identified, cancer-related PTSD symptoms can be treated.



Matthew Doolittle is a psychiatrist, Katherine Duhamel (center) is a health psychologist, and Jeannie Otero is a research student affiliate in the Department of Psychiatry and Behavioral Sciences. MSK was a pioneer in considering the mental healthcare of people with cancer. Today, the department is the largest national resource for training and research in psychiatric oncology.





Erin Geddis Cummings has been a survivor of Hodgkin lymphoma for 46 years. She was diagnosed at age 15 in 1972 and grew up in Summit, New Jersey. She has a master's degree in social work and spent the past several years volunteering at a therapeutic riding program outside of Boston. She has been married to her husband, Rich, for 35 years, and they have four children, ages 18 to 31, all of whom were adopted from South Korea.

## A Mother's Prayer

By Erin Geddis Cummings

Like any good Catholic, I learned early in life to pray for everything I wanted. I prayed to stay out of trouble, to pass a math test, to have a boy look at me. I prayed that my parents would stay together. And I prayed that I would survive cancer and that I'd live long enough to go to college. I prayed that someone would love me, with all my scars, and that someday I might even get to be a mom.

I was lucky. God answered most of my prayers. At 30 years of age, I had lived well beyond the five years I was given when diagnosed with stage IV Hodgkin lymphoma. I was married to a wonderful man who not only loved me but accepted the fact that I may never have children. Rich's response was, "It's OK. We can always adopt. We can still have a family." I believed him, but I wanted more.

I wanted to be pregnant. I thought that being able to give birth after fighting my way back from pure hell would be the ultimate gift. So once again, I started to pray.

**I prayed that someone would love me, with all my scars, and that someday I might even get to be a mom.**

Rich and I tried for months to conceive, only to be continually heartbroken. Our bedroom began to resemble a laboratory. There were charts and graphs on my bedside table and a thermometer that I dutifully used

every morning before I got out of bed. Having sex became a job instead of an act of passion.

Meanwhile, it seemed as though the rest of the world was pregnant. Many of our closest friends were expecting, and they made it look so easy, like having kids was as simple as growing a Chia Pet. Rich and I were exhausted from trying to be joyous for our friends while keeping our resentment to ourselves.

I was overwhelmed with guilt. I couldn't give my husband a baby, and I felt greedy and self-centered to want anything more than to have survived cancer. We began to explore adoption. Then one day, completely unexpectedly, my temperature started to climb. I was sure that I was sick again with Hodgkin's. I had all the signs: low-grade fever, lethargy, itchy skin. I scheduled an appointment with my doctor and waited for the blood tests to come back. And there it was. I didn't have cancer — I was pregnant.

We were stunned. Rich and I secretly celebrated our good news, afraid to

■ *Continued on page 8*

## Resource Review:

# Cycle for Survival

By Alexandria Woodside



Alexandria Woodside has worked at Memorial Sloan Kettering since 2014. She was part of the Adult Long-Term Follow-Up Program, then moved to the Gerstner Sloan Kettering Graduate School of Biomedical Sciences, and is now the Survivorship Program coordinator. She is originally from Chicago but has found a home in New York City. A participant in Cycle for Survival herself, she has led a team for the past three years.

Cycle for Survival is the movement to beat rare cancers. The unique events help Memorial Sloan Kettering fund research into treatments for people with a rare cancer. All of the money raised goes directly to lifesaving research and clinical trials. About half of all people with cancer have a rare form of the disease. Rare cancers include brain, pancreatic, ovarian, and stomach cancers, as well as all types of pediatric cancers, plus many others. However, research on many rare cancers is drastically underfunded. People with rare cancers often have limited or no treatment options.

The money raised is allocated within six months of Cycle for Survival's annual

events. The indoor team cycling rides were started in 2007 by David Linn and his wife, Jennifer Goodman Linn, an MSK patient who passed away in 2011. In 2009, it became an official MSK program that is owned and operated by MSK. Today, nearly 35,000 people come together nationwide each year to ride and fight cancer. The events take place in 16 cities across the United States throughout January, February, and March. Cycle for Survival events are for riders of all levels of athletic ability. Team members can pedal hard or hardly pedal! Instructors from Equinox, Cycle for Survival's founding partner, lead the high-energy rides. Anyone interested in joining is welcome to help raise money and ride.

Cycle for Survival and its community are dedicated to improving the way cancer is diagnosed and treated. The mission is to advance important research where little to no funding exists. The direct funding has drastically reduced the time it takes for treatments to reach patients. In some cases, the time span has been cut from years to months.

Registration opens each year in September. It's free to register, though each bike has a minimum fundraising requirement of \$1,000. Teams have four to eight teammates per bike. The events are four hours long, and teammates split the 50-minute rides. Events kick off each hour with an inspiring speech from MSK patients, doctors, caregivers, researchers, and cancer fighters. Together, everyone will laugh, dance, cry, and ride.

About half of all people with cancer have a rare form of the disease.

For more information about Cycle for Survival and how to participate, visit [CycleforSurvival.org](http://CycleforSurvival.org) or email [CycleforSurvival@mskcc.org](mailto:CycleforSurvival@mskcc.org).







Abby Wood, 32, works for a technology company in Chicago, where she lives with her fiancé and two dogs. She loves to travel, cheer on the Cubs, and spend time with her family. She makes frequent trips back to New York, where she enjoys reuniting with her MSK care team.

## Cycling for a Cause

By Abby Wood

I first learned about Cycle for Survival when I was back at MSK for an annual checkup. When I was diagnosed with stage IV Hodgkin lymphoma in March 2008, I promised myself that after I got through chemotherapy and radiation, I would do what I could to help other people with cancer. As soon as treatment ended and I regained my strength, I started fundraising for various cancer organizations. However, I always wanted to do something for MSK specifically. After all, MSK was my home away from home for many months, the place that saved my life, and a place dedicated to doing the same for so many other patients and their families. I'm not able to run with Fred's Team due to a bone disease in my hips caused by the chemo, so when I read about Cycle for Survival, I knew this was my opportunity to help MSK fight rare cancers.

Due to hip surgery in 2013 and then a full hip replacement in late 2014, my Cycle for Survival debut kept getting pushed back. But in 2015, I was the

**There were people of all ages and from all backgrounds, but everyone came together with one goal: to raise money to help more people reach that survivor status.**

healthiest I had been since 2008 and was ready to sign up as a team captain, put together a solid team, and raise money to help beat rare cancers. I was

living in New York City at the time and was so excited to participate in my favorite city — the very place where I had fought my battle. Family members, friends, and coworkers all joined “Abby’s Army,” and we had an extremely successful fundraising run. My twin sister and a few of my closest friends flew in, making the event even more meaningful to me.

The room was full of survivors, families and friends of those who had lost their battle, current fighters, and people committed to the cause. There were people of all ages and from all backgrounds, but everyone came together with one goal: to raise money to help more people reach that survivor status. Tears rolled down people’s cheeks as they remembered loved ones who fought so hard to live, and strangers hugged to celebrate those who were still with us. As a survivor, the emotions overcame me. I was so proud to be standing in that room on two legs and so determined to help others achieve the same outcome. I had participated in many fundraising events in my life, but never before had I witnessed the energy, dedication, and passion that I saw that morning at the midtown Equinox.

■ Continued on page 8

■ Continued from page 5

say a word to anyone before the first trimester was over. We dared to dream of our red-haired, freckle-faced boy or girl. We tried out every Irish-sounding name we could think of. I went through each day in a daze, resting my hands on my stomach, willing my baby to be safe. At night, I not only prayed, I got down on my knees and prayed, begging God to stay by my side.

Before we had our first ultrasound, it was over. I had an ectopic pregnancy. I was whisked into emergency surgery and woke up to the sight of my husband, eyes filled with tears, wordlessly wrapping his arms around me, trying with all his might to take away the pain.

It was hard not to feel that cancer had won again and that God was, indeed, bent on testing the limits of my faith, but I refused to give up. I would be a mother. We *would* have a family. In the end, Rich and I decided to adopt a child from South Korea, a child who needed us as much as we needed her.

We've since adopted four children from Korea, two of whom had serious medical issues and would have their own fight for survival. Rich and I never hesitated. We may have learned about perseverance the hard way, but the joys we've earned in the end, the beautiful family we now call *ours*, has been worth it all.



Continued from page 7

Cheers and tears intertwined to make it a truly beautiful Saturday.

Knowing my story, the Cycle for Survival team asked me to speak to

kick off a ride. I stood up in the middle of the room wearing the lucky Cubs hat I wore throughout chemotherapy, and I thanked my friends and family who were riding with me that day and who had worked hard to raise more than \$20,000. As I told my story, I knew there were so many people in the room who had lost friends, mothers, fathers, sisters, brothers, daughters, sons. It invigorated me to continue doing what I could to help MSK and Cycle for Survival find answers to these rare cancers that plague our world. Now living in Chicago, I can't wait to see Abby's Army T-shirts fill a Chicago Equinox in the winter of 2019 — and I know that the love, emotion, commitment, and inspiration we feel in the room will continue to push me, and many others, to return year after year to this incredibly uplifting event.



Memorial Sloan Kettering  
Cancer Center

*Patient Editor*  
Eileen F. Gould

*Managing Editor*  
Alexandria Woodside

*Advisory Committee*  
Melanie Bilkis  
Wendy Bonilla  
Joanne Candela, ANP, MPH  
Zana Correa, NP  
Patrick Dooley  
Stacie Corcoran, RN, MS  
Diane Dunst  
Darren Feldman, MD  
Barbara Golby, LCSW  
Ellen Greenfield  
Judith Kelman  
Mary Ellen McEvily  
Ann Pfister-Brown  
Nirupa Raghunathan, MD  
Larissa Regala  
Robert Sidlow, MD, MBA  
Clare Thomas  
Seeta Verron, NP

*Produced by the*  
Department of Communications

*Bridges* is a publication of the  
Cancer Survivorship Center at MSK.

### Memorial Sloan Kettering Blood Donor Program

Help MSK patients by donating blood or platelets to the MSK Blood Donor Program. Both general and directed donations are welcome. Please call for hours and more information.

**MSK Blood Donor Room**  
Schwartz Building Lobby  
1250 First Avenue  
212-639-7648 or 212-639-8177

Interested  
in sharing  
your story?

Please visit  
[www.mskcc.org/bridges](http://www.mskcc.org/bridges)