

Bridges

Connecting Cancer Survivors



The Shared Experience

By Seth Frankel

In 1995, at just 14, I was diagnosed with primitive neuroectodermal tumor, a soft-tissue sarcoma, in my chest wall. Instead of experiencing the awkward fun of starting high school, I went through the chemotherapy, surgery, and radiation that are familiar to so many of us. Since then, I like to think I have had a blessed life. I attended my dream college and had the opportunity to travel through Europe and China. Around five years ago, I got married and have two wonderful children. Of course, things weren't always so smooth. I had two scares in 2003 and 2007 when the 11-inch surgical scar across my chest swelled up like a balloon. It turned out it was "only" a blood clot that could be surgically repaired, but there were tense moments waiting for the test results.

I've met many survivors over the years, and despite our substantial differences, we have a shared experience no matter our gender, race, ethnicity, or economic status. I've noticed seven particular traits that I have in common with virtually every survivor I meet:

Fear: There is a pervasive fear as a survivor. Fear that aches and pains, stomach flu, or a swollen gland is actually something much, much worse. Fear that you'll be taken from your family too soon. Fear that you have to summon the strength to do everything all over again. It's enough to drive you mad.

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Seth Frankel has been cancer free for more than 20 years. He works as a lawyer in Manhattan and lives in New Jersey with his wife and two sons. In the little spare time that having two young kids permits, he loves to read and play (or watch) sports of any kind.

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Memorial Sloan Kettering
Cancer Center

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Editorial

By Eileen F. Gould

This issue of *Bridges* begins our ninth year of publication and we continue to be amazed by all the wonderful stories and professional articles that come our way. Over the years, we have published about 160 personal stories from MSK patients and caregivers as well as 32 articles from clinicians who have graciously shared their extensive knowledge on survivorship topics. We appreciate everyone who has shared their personal journeys and challenges of survivorship.

With the establishment of the Cancer Survivorship Center in 2014, MSK continues to be a

trailblazer in The World of Cancer survivorship. It is predicted that by 2020, there will be 18 million cancer survivors in the United States. As new treatments and therapies are developed, quality of life and outcomes for cancer survivors will continue to improve as new information is shared. In the eight years of this publication, the field of survivorship has grown immensely, and the wealth of information and available resources has become quite vast at this institution. We look forward to continuing to share informational articles and more stories of hope and survival.



Where Are They Now?

Harrie Bakst

A week after he turned 22, New York University student Harrie Bakst was diagnosed with a rare cancer, adenoid cystic carcinoma, in his salivary glands. After surgery and 33 radiation treatments at Memorial Sloan Kettering, Harrie walked out of the hospital on June 5, 2007, cancer free. Five months later, he ran past the hospital on First Avenue as a member of Fred's Team in the New York City Marathon alongside his brother Rich, determined to prove to himself that he was alive and OK.

Nearly a decade later, Harrie, who remains cancer free, is a partner at the leading philanthropic consulting firm Weinstein Carnegie Philanthropic Group, and is still running with his brother. Most importantly, Harrie and his wife, Amy, will welcome their first child in June. "When you have your health, anything is possible, and MSK gave me that opportunity," he says. "In the grand scheme of things, everything else is easy. There isn't a day that goes by where I am not reminded of how thankful I am toward MSK."



Ask the Survivor

By Erica S. Goldman-Brodie

Erica S. Goldman-Brodie, a retired schoolteacher, part-time teacher-mentor, and author, lives in Riverdale, New York, with her husband, Rabbi Joseph Brodie. She was diagnosed with stage IV clear cell endometrial carcinoma on September 10, 2004, and has been in remission since June 1, 2005.

Since becoming a survivor, how have you taken charge of your own physical health? Are you more proactive in taking care of yourself?

I've found that walking on the treadmill is calming and releases tension, not to mention promotes weight loss. I also keep track of my food and exercise on a great cellphone app that helps me manage my nutrition on a pie chart. It doesn't lie even if I'd like to lie to myself!

I've also learned that early treatment can save a great deal of aggravation and that it's my responsibility to tell my doctors of any changes. But truthfully, there have been times that I've waited longer than I should have or been dismissive of symptoms. I'd like to chalk this up to benign neglect, but I'll admit it's possible that it's my way of dealing with post-treatment anxiety.

How has your life changed since retirement and how have you stayed busy?

I used to think I would never retire and even dreaded the idea. I loved teaching and after 37 years it still brought me great joy and satisfaction. It wasn't until I started treatment that I took some time off and ended up discovering a whole new experience of living outside of teaching.

Now that I'm officially retired, I take interesting courses and make frequent trips to the beautiful New York Botanical Garden with my husband. We've also become members of museums, attend concert rehearsals during the day and, best of all, we can meet friends whenever we want.

Much to my surprise, I truly love retirement. My husband jokes that he doesn't know how we had time

to work! So as much as I loved teaching, I'm enjoying retirement at least as much.

How has survivorship and getting older affected your friendships and relationships?

When I was first diagnosed, I spoke to a friend who is a cancer survivor. She said, "If you asked me now whether or not I'd want to relive my life with or without the cancer, I'd answer, 'WITH!'" At the time, I thought she was truly crazy! Looking back, I think I know what she meant. Not only do I have a very deep appreciation of the past 11 years of life, but I've also looked back upon my entire life with so much more gratitude and appreciation than I ever had before.

Three close friends were like Elijah the prophet, always showing up unexpectedly when needed most, while I was in treatment. They checked in on me daily, came with me as my head was shaved, attended appointments, and even made jewelry especially for me, and were always able to make me laugh during treatments. We still meet regularly and go through hoops to make sure that we can all be there. It's a tonic like no other.

To celebrate my 70th birthday, I recently contacted two high school friends. Unbeknownst to me, they had not seen each other since we graduated in 1964. My memories of them were confirmed; they were as lovely, fun, articulate, and caring as I had remembered. The several hours together melted away the many years of absence.

That encounter inspired me to reach out to people in my life now and people who had previously been in my life to recognize and salute their importance to me. It's been so rewarding.

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When the Elephant in the Room Is Cancer

By Katherine Callan-Montemarano

Katherine teaches English at Staten Island Technical High School. Formerly, she was a magazine writer and editor. She is a wife, stepmom, friend, daughter, daughter-in-law, aunt, sister, runner, yogi, and breast cancer survivor.

I have always been driven by goals and positive energy. I make daily to-do lists in a notebook; my bookshelf is lined with motivational titles; my husband and I attend a wonderful faith community in Park Slope, Brooklyn, where we live.

In the summer of 2014, when I learned of my diagnosis of breast cancer — stage I, lumpectomy required — I experienced what I imagine thousands of other women have too: angst, anger, and worst-case-scenario thinking. I told myself to stay calm and to stay strong. Oddly, I didn't want to hear positive thinking. I wanted people to meet me at my place of despair and to acknowledge my diagnosis for what it was: terrifying and life altering. My cancer was a no-spin zone.

So what do you say to a diagnosis of cancer? What do you do? Stories and advice are meant to help but often don't. How do you address the elephant in the room? Throughout my diagnosis and treatment, I was the recipient of words and gestures that were profoundly moving and comforting. They are not the answer — there is no answer. But they provided me with great solace, so I pass them along here.

My stepson Matthew, 12 at the time, told me he was glad that I got cancer when I did because medicine is more advanced than ever. He taught me gratitude. My 16-year-old stepson Thomas said I'd earn another label: marathon runner and breast cancer survivor. He reminded me of my strength.

I received an outpouring of support from my circle of running friends. Rachel wrote: "You have a huge and loving running family. Reach out and share your struggle. It makes us all stronger." Alex — a wife, mother, ultramarathoner, and doctor — sent homemade biscotti and healing tangerine tea. My dear friend Lisa brought me a flower every other week. She said the flower was life and that it was beautiful. What a perfect place to focus.

Breast cancer sucked me into a world where doctor appointments dominated, especially during my eight rounds of chemotherapy. I shared what I was going through with staff and students at my high school, so they wouldn't worry during my intermittent absences. Ms. Labora and Mr. Terrusa gave me holy water. Mr. Misciagna told me,

"I have 237 people praying for you." Those prayers and blessings made me feel protected and supported. At times, it was hard to accept acts of kindness, to receive and receive. But my husband, who spent two years in his twenties nurturing his wife before he lost her to cancer, reminded me that to decline an act of kindness was to deprive someone of a blessing.

Text messages — "I am thinking about you and saying prayers for you today," or "The journey is almost over," or a simple "How's it going?" — were all little outreaches that helped a lot.

During radiation, I commuted to MSK for daily treatments. After I was completely done, I was at school grading papers when my students walked in, carrying three cakes and a card in the shape of the breast cancer ribbon. To me, the end of treatment meant resuming my schedule, but for teenagers, it was a reason to celebrate. They were right; it's hugely important to acknowledge milestones.

Dr. Arthur Caliandro of the Marble Collegiate Church I used to attend

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ASK THE PROFESSIONAL

Blood Donor Program

By Joe Licata, Director of the MSK Blood Donor Program

More than 1.6 million people were diagnosed with cancer last year. Many of them will need blood and platelets — sometimes daily, if they are receiving chemotherapy treatment.

On average, leukemia patients require more than 20 platelet transfusions over a six-month period. Platelets are particularly beneficial for leukemia and bone marrow transplant patients because they greatly reduce the chance of rejection. Here at Memorial Sloan Kettering, we transfuse more than 40,000 units of blood products to our patients each year, many of whom are children.

In the Northeast, only about 3 percent of the eligible population donates blood products. The percentage is a little higher in other parts of the country, but not nearly high enough. There is no substitute for human blood, so we rely on the public to help maintain an adequate supply for our cancer patients. Donating blood once is helpful, but we encourage people to make an effort to donate as often as possible. We also have a program that allows people to designate their donation for a specific patient.

How often can I donate blood?

Donating blood is a simple and safe procedure. Whole blood can be donated every 56 days, for a maximum of six times a year. Platelets can be donated once every seven days and up to 24 times a year.

How long does it take to donate blood or platelets?

Donating blood takes only about an hour; donating platelets takes about two and a half hours.

How old do I have to be to donate blood or platelets?

Anyone between the ages of 17 and 75 who meets the eligibility requirements may donate; 16-year-olds may donate blood with parental consent, and donors over the age of 75 may donate with a physician's written consent.

What should I do prior to donating blood or platelets?

Eat well and drink plenty of fluids. It is always best to donate on a full stomach and increase your fluid intake beforehand. When donating platelets, you cannot have had any aspirin or aspirin products within the prior 72 hours and no anti-inflammatories like Advil or Ibuprofen within the prior 48 hours.

If I have had cancer, can I donate?

There are only a few cancers that would preclude you from donating blood or platelets. If you have a history of leukemia, lymphoma, myeloma, or Hodgkin's lymphoma, you are permanently prohibited from donating. Most other cancers are able to donate again. Cancers in remission defer for one year after treatment, including for breast cancer patients taking tamoxifen or arimidex.

What else should I know about donating?

Our excellent staff will make you feel comfortable and help you throughout this process. You can make an appointment to donate during a time that is convenient for you. Our donor room is open seven days a week starting at 8:30 AM every morning, with evening hours on Tuesday, Wednesday, and Thursday. We offer five hours of free parking for anyone who comes in to donate.

Find out more info about our donor requirements on our website at www.mskcc.org/giving/blood or call the Memorial Sloan Kettering Blood Donor Program at 212-639-8177 with any questions or to make an appointment.

Our Blood Donor Room is located at 1250 First Avenue, between 67th and 68th streets.



Exercise Made Me Feel Alive

By Yariv Kafri

I am a 50 year old father, husband and cancer fighter who was diagnosed in the fall of 2013. My mission is to inspire, motivate and empower fellow survivors to incorporate exercise into their healing process and be proactive about their future.

Imagine this: You're healthy and active with a wife and two kids. An accident while out surfing takes you to the emergency room, where a scan shows that you have a brain tumor. It's metastasized stage IV lung cancer. Your world has been completely rocked and it doesn't make sense. Brain surgery and chemotherapy are next, but just 22 months later you're completing the TransRockies Ultramarathon, running 58 miles and ascending 9,000 feet.

I Have Cancer

It's difficult to describe how much my own and my family's lives changed after I was diagnosed. I was in disbelief! How could the body that I trusted betray me like that? How would my family continue without me? The physical implications, learning to live with cancer, the emotional impact — it was an ongoing rollercoaster, full of fear, worries, and hope. We tried to stay in the moment by focusing on good things happening in the present and avoiding the scary, negative thoughts that always tried to creep in.

Outrunning Cancer

I had been in top physical shape before my diagnosis. While receiving treatments I thought about getting back to exercising. Just ten days after my brain surgery I was cycling again with my buddies. It made me feel great — alive, independent. This quick bounce-back was attributed to my fitness. Then came chemotherapy — and that's a whole different story. Initially, recovery was quick, but after four rounds of aggressive chemo my strength and stamina had disappeared.

I did what was natural for me: exercise, stay in the moment, and be thankful. My attitude was having a positive impact on my family, me, and other survivors, which is how the idea to give back to fellow survivors emerged.

It's All about the Journey

I didn't allow my cancer diagnosis to stop me from defying limits and conquering my dreams. In fact, living with cancer as an athlete inspired me to create a nonprofit organization designed to empower and motivate cancer patients to be physically active. Every year I plan to participate in a unique athletic event to inspire and motivate other cancer patients and survivors to exercise. Participating in such events requires discipline, commitment, hard work, and perseverance.

The TransRockies Ultramarathon was amazing, but the road I took leading to this event was even more remarkable. My journey began 22 months before; upon completing chemotherapy I was unable to walk more than half a mile. I started exercising, watching exercise videos, and later retaining a running coach. My body lost so much muscle mass that I was constantly injured and everything hurt, but I kept training to be able to ramp up the distance.

I arrived at the location of the ultramarathon well prepared but was caught off guard. I had dehydrated during the days leading up to the race while acclimating to the altitude. Day one was a nightmare, but I hydrated like crazy overnight and completed the event strong. I was so proud and received such great feedback from fellow survivors and others — amazing gratification.

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What's next?

My primary goal is to prolong my life, to be here when my sons mature into young men, and to spend time with my wife. I plan to participate in an ultra-endurance event once a year — something that will challenge me mentally and physically and draw attention to our mission: motivating, inspiring, and empowering fellow survivors to exercise.

Oh, and I started training for the 2016 SEAPaddle, a 25 mile stand-up paddleboard event that circumnavigates Manhattan!

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Pain: My scar always feels a little off. Despite almost 21 years since my surgery, it just never feels exactly the same. There are times it will hurt more than others, but the best way to describe it is that it's always there. Even an accidental brush up against my scar can hurt. Ending treatment does not mean the pain stops.

Guilt: There's a guilt that comes with being a survivor. The "why me?" you ask when you are diagnosed is replaced by a "why me?" about being lucky enough to survive when so many others are not as fortunate. Even the elation of finishing treatment was balanced with the guilt of leaving friends behind to fight without me.

Helplessness: Whenever anyone I know is diagnosed with cancer, the impulse is to reach out. But every cancer is different, every person is different, and every treatment is unique. Not everyone wants to hear encouragement. You want to help, but sometimes all you can say is "hey, I had cancer and survived. So will you."

It's not all negative, of course. There are also some remarkably positive traits that we share as survivors:

Strength: There is an obvious strength that comes with surviving. The strength of knowing no matter what life throws at you, you have done something extraordinary. You beat cancer — you can do anything.

Perspective: Yes, it is the cliché to end all clichés to say beating cancer gives you perspective. But it is true. The little things do not bother you as much anymore. They are just that — the little things.

Pride: Most importantly (for me, at least), surviving creates pride. People get embarrassed by physical imperfections — not me. I am proud of my scars and am eager to show them off, even if most people would prefer that I keep my shirt on in public. They show the war I've been through and are my badge of honor. They show me anything is possible.

That is what being a survivor is all about. We may be neurotic about our health, but behind that neurosis is a strength that is virtually unparalleled.

Rising Voices

is a fun and lively singing group just for patients and survivors. Open to all MSK patients, Rising Voices is a free, supportive activity sponsored by the Integrative Medicine Service.

To join, please contact Jackie Konkowski at konkowsj@mskcc.org or call 646-888-0800.

Resources for Life After Cancer (RLAC)

RLAC welcomes survivors to participate in programs that encourage healing through education and support.

Please see the online calendar at: www.mskcc.org/livingbeyondcancer.

Visible Ink™

A One-on-One Writing Program for MSK patients

Interested patients will work individually with the guidance, encouragement, and support of a professional writer on a topic and project of their choice. This program is FREE. All levels and writing interests welcome.

For more information or to arrange a writing session, please contact Judith Kelman at 212-535-3985 or kelmanj@mskcc.org.

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
212-639-7648/212-639-8177

Connections

is an online community for patients and caregivers. It provides a venue for conversations, support, questions, and companionship.

To register, visit: www.mskcc.org/connections.

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preached that the place where people truly connect is pain. We do not always need to be talked out of it or told everything will be OK. Now I'm in the last stage of treatment: a daily pill that should reduce my chance of reoccurrence by 40 percent. There are side effects, but I thank God for early detection.

It wasn't that long ago that people were afraid to say the word "cancer." It was the "Big C." But we're in a cancer awakening.

How do you make cancer normal and not awkward? It's neither by ignoring it nor by fawning over it. When we learn that our friends and colleagues, neighbors and sisters have been afflicted, we can meet them in their place of pain, affirm who they are, and accompany them as best we can on their journeys.

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Has your philosophy of life changed as a cancer survivor?

My husband recently had open-heart surgery and thankfully, he's fine. During his and my own health scares, I had a renewed appreciation for modern medicine and its practitioners, who are able to prolong the quantity and the quality of life. They didn't do it alone; friends, family, and community all sustained us. As I prayed for Joe's survival — as he had done 11 years before for mine — I realized that our human, mortal life is finite and living and sharing an ethical, love-filled, love-giving, and love-getting life is priceless!

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Patient and Caregiver Volunteer Program

The Patient and Caregiver Volunteer Program connects current patients and caregivers to volunteers who have experienced a similar diagnosis or circumstance related to cancer. If you are a former patient or caregiver of someone who has completed treatment, please consider becoming a Patient or Caregiver Volunteer.

For more information, contact
Wendy Bonilla at 212-639-5007 or
patient2patient@mskcc.org.



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