

Bridges

Connecting Cancer Survivors



The Cycle of Life

By Valerie David

I am now a proud two-time cancer survivor — non-Hodgkin's lymphoma in 1999, and then breast cancer in the summer of 2014, both treated at Memorial Sloan Kettering (MSK).

One of my favorite activities is to ride in the annual 40-mile New York City TD Five Boro Bike Tour. I use it as a fund-raiser for the Leukemia & Lymphoma Society, and this year I added a breast cancer charity. I look forward to it every year, but this year was different.

After my stage II breast cancer diagnosis, a lumpectomy followed in September 2014, then chemo in November and December. I started radiation on February 2, 2015, finishing my last treatment on February 27. I thought, How in the world would I be able to bike 40 miles on May 3, only two months after completing treatment? It seemed unattainable. When I mentioned biking to my MSK doctors, everyone was so encouraging and urged me to register, so I did!

Fast-forward to May 2, the day before the ride: I was convinced I wouldn't finish. My treatment, including the four weeks of radiation, had tired me out, and I had just recovered from a painful post-treatment radiation burn.

Then it was Sunday, May 3 — the day of the bike tour. I woke up at 6:15 AM, terrified. There were four of us

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Valerie David, a two-time cancer survivor, is an editor, writer, playwright, and actor. She performs improv around New York City and has written play reviews for Time Out magazine. Valerie, with her college friend Amanda Powers, cofounded a charity bike fund-raiser called Cycle of Hope to help raise money for cancer organizations. She is also a patient speaker at the Leukemia & Lymphoma Society's Team in Training events.

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Interested in sharing your story?
Please visit www.mskcc.org/bridges



Editorial

By Eileen F. Gould

I recently attended two very informative talks sponsored by Memorial Sloan Kettering's Resources for Life After Cancer

(RLAC) and continue to be amazed at the wealth of information and support available to patients at this institution.

At one of the events, Dr. Kevin Oeffinger, Director of the Cancer Survivorship Center, provided updates on survivorship research and discussed patient needs for the growing population of cancer survivors. Currently, more than 12,000 survivors are seen in the nurse practitioner-led clinics, with another 800 survivors seen in both the Adult Long-Term Follow-Up clinic and the Pediatric Long-Term Follow-Up Clinic. MSK has what is likely the largest survivorship program in the country and serves as a model for others.

The other talk I attended, which focused on osteopenia and osteoporosis, included a panel of MSK experts from rehabilitation medicine, endocrinology, and nutrition. The topics ranged from which foods enhance bone health to what bone density means. The presentation concluded with an exercise instruction led by members of the physical therapy team that aimed at improving bone density and postural alignment.

As the field of survivorship continues to grow dramatically, we are so fortunate that MSK is a trailblazer in this area and has so many excellent experts who can share their knowledge with both patients and other clinicians.

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us riding together. At the start line, the bullhorn sounded at 8:30 AM, and we were off. As I peddled, I passed mile ten, then mile 20. I felt great. I was shocked! I thought, Maybe I can do this!

When I hit the Verrazano Bridge, I knew it would soon be over. Right after the bridge comes the "Finish Festival" to celebrate your 40-mile victory. My heart began to race with excitement – I was at the bridge. During the uphill climb, I pumped my legs even harder. As I went up the incline, flashbacks of the last eight and a half months flooded my mind – images of my bald head, chemo drips, and IVs; my surgery and radiation; ER visits due to complications; fevers; allergic reactions; the physical and mental

anguish; hearing the words "You have breast cancer"; the CAT scans, mammograms, biopsies, needles, and shots; and the sheer anger of having cancer a second time in my life.

Tears of joy came pouring out when I hit the midpoint of the bridge. It was only downhill the rest of the way, but not really. I wasn't spiraling downhill in the way cancer had made me feel as if I were. It was in that moment that I realized it was the best thing in the world to go downhill. As I descended down the last half of the bridge, those flashbacks of all the pain – the fear, that fury – melted away as I rode it out of my system. I couldn't have been happier to descend, because it meant I won. I beat cancer! Twice!

As I crossed the finish line, I yelled to the staff, "Guess what! I just completed breast cancer treatment two months ago! I did it!" I don't think I've ever felt more triumphant than I did that day, and it forever changed how I look at myself and what I can accomplish. I believed in myself again. I will forever treasure this life "cycle."

PS: This fall I upped my game: I rode 55 miles in the NYC Century Bike Tour, helping to raise money for two cancer organizations.

I would like to thank MSK, my friends, and family for all of their support.



ASK THE SURVIVOR

Living with Scars

By Robin Glassman

Robin Glassman is an artist and a long-term survivor of Hodgkin's lymphoma. Between the ages of 12 and 15, she underwent large doses of radiation therapy, two-and-a-half years of chemotherapy, and several surgeries. She has been disease-free for 40 years.

How have your scars impacted you emotionally and socially?

My largest scars have been with me for so long that they are now part of me, but that hasn't always been the case. When I was young, I was very self-conscious of my scars, and it was difficult to deal with all the emotions and restrictions that came with my illness. My scarred body was a constant reminder of the isolation and loneliness I was going through. Socially, I pretended nothing had changed and I tried to be a "normal" teenager. But deep down, I knew I couldn't cope with any of the changes that were happening inside and outside my body. Although this had more to do with the impact of my disease, how can you separate the two?

Now, with a larger support system and the knowledge, growth, and maturity that age and therapy have given me, I accept the old scars and honor the new ones. Even though they can cause pain and discomfort as they heal, I am grateful for the procedures and surgeries that have brought me to where I am today. That being said, it is still difficult to look at myself and see the scars some days. But I continue to work on this.

How do you discuss your scars with people you know? Do you ever feel the need to address them to strangers?

Because most of my scars are only visible when I am unclothed, and because I am in a committed relationship, the conversation usually revolves around the latest surgery and the sensitivity of the site. When I started dating, I would use the person's reaction to my scars and my medical history as a reflection of his character. I am glad those days are over. Now discussions with other patients usually take the form of comparing notes. Nowadays, talking about surgeries and illness

is second nature and much more socially acceptable. Friends offer advice on ways to promote quicker healing of scars and often share their stories. It is a conversation starter, and if asked, I am very open to discussing, showing, or explaining my scars.

Have you sought dermatologic treatment? If so, how helpful has it been?

After I was diagnosed with and treated for basal cell carcinoma (BCC) in 1996, which can be one of the many long-term effects of the mantle radiation for Hodgkin's lymphoma, I began seeing a dermatologist regularly. It is important to be followed by a dermatologist who knows how to detect for BCCs caused by mantle radiation, and the doctors I see are up to date on the latest treatment. Currently, I'm in a study using laser ablation to remove the more superficial BCCs that will hopefully leave less of a scar than the current MOHs treatment (also known as chemosurgery).

Do you have any advice for other survivors with scars?

We are all unique and handle our health issues differently, so trust your instincts. Ask your clinicians questions, and if you don't understand the answer, make sure you do before leaving their office. Also try to reach out to other patients and survivors. Unlike when I was diagnosed and treated, there are now so many resources out there, including Memorial Sloan Kettering's Resources for Life after Cancer. They have services, programs, and support groups specifically for survivors. Be kind and gentle to yourself; you deserve it. A lot has changed and happened to shake up your world, so take the time and space you need to gather strength and equilibrium. Your body will thank you.



Adding Zest To Life after Cancer

By Melanie Young

Breast cancer survivor Melanie Young is an author, radio-show host, and certified health coach. She lives with her husband, David Ransom, in the lower Hudson Valley and enjoys yoga, hiking, cooking, reading, and writing. They are the parents of Sazerac, a three-pound rescued male Maltese.

For years I lived a delicious life hobnobbing with chefs and visiting the great wine regions of the world for my job as a food and wine public relations agency owner. In 2009, during a trip to Italy, I found a lump in my breast through self-examination and was ultimately diagnosed with stage 2A breast cancer. One of the immediate questions I asked myself was, “Did my rich diet and stressed-for-success lifestyle trigger my diagnosis?”

Thanks to my great team of doctors and nutrition specialists at Memorial Sloan Kettering, I took steps to improve my diet and exercised regularly to keep up my strength during my four surgeries and five months of chemotherapy. Sadly my beloved father died from cancer shortly after my bilateral mastectomy. I started writing in a journal to re-channel the grief I felt over losing both my father and my breasts.

In the years following my treatment I was still feeling a good amount of

stress over what had happened in my life. I decided to close my PR agency in 2011 and pursue my dream of being an author and sharing my own voice rather than crafting messages for clients. After two years pitching my book idea, I landed a publisher. Today I am the author of two award-winning books that help newly diagnosed women facing breast cancer — and anyone facing life-altering challenges — reframe and reset emotionally.

I also became passionate about helping others improve their health and enrolled at the Institute for Integrative Nutrition to become certified as a health coach. I believe the healthy changes I made going into treatment helped keep me strong during my year of living surgically and chemically. My diet today is still rich in flavor and deliciousness, but healthier all around. I believe a healthy diet is about adding in better foods like fresh fruits, vegetables, lean protein, healthy oils, whole grains, and fiber and crowding out foods

that are processed or contain too much saturated fat and sugar. I still enjoy wine, and it is part of my professional life. I don’t believe in giving up foods you enjoy; I just believe in enjoying them with mindful moderation and conscious consumption.

In 2014 my husband, David Ransom, and I moved out of New York City for a Greener-Acres life in the Hudson Valley. Our fast-track life is a bit slower but no less fulfilling. After years of dining out almost nightly in restaurants, I learned to cook, enjoy the outdoors, and take it slow, which is better for managing stress. Before my diagnosis I was working at an unhealthy pace and putting my business and clients first and my health second. Now I put health and self first. Nothing is more important.

My message to anyone facing cancer is that you may not have chosen to have cancer, but you can choose how you want to be treated and how you want to treat yourself moving forward.

Not Just Surviving, But Thriving

By Erin Berrios

My name is Erin Berrios, and I am a SURVIVOR!

On July 1, 2011, at the age of 32, I was diagnosed with lymphoblastic lymphoma. I had a mass in my chest the size of a peach and the tumor had spread to my bone marrow. My daughters were almost one and three years old, and I had recently celebrated my sixth wedding anniversary.

I decided to get mad at this cancer and fight back. It would not prevent me from seeing my children grow up. It would not stop me from living the fun-filled life of my dreams. This was war!

After my third round of chemotherapy, my doctors stood over my bed looking sad. My body was not responding to the chemotherapy regimen; I needed a bone marrow transplant.

We decided to go to Memorial Sloan Kettering. My doctor, chief of the program, asked me to give him a year of my time and in return he would give me back my life.

All six of my siblings were tested as possible donors but none of them were a match. I had to take a not-so-perfect match, which could involve more risks and complications. The transplant was scheduled. By the grace of God, my transplant was delayed due to an infection and during that delay, by wonderful coincidence, someone signed onto the Bone Marrow Registry who was a perfect



I'm married to the love of my life, have two beautiful little daughters, and had a cancer diagnosis at 32 years old. I hope my story, from diagnosis to treatment and healing, will inspire people in their fight and survivorship by letting them know they too can live their lives again.

match for me. During my month in the hospital, I endured total-body radiation, chemotherapy, and other treatments before receiving my donor's cells. My transplant took place on February 16, 2012 — my new birthday.

I had to stay in New York City for 100 days after the transplant. My counts started to climb as my donor's cells grafted. Bone marrow biopsies and PET scans showed no sign of cancer, no markers, no disease, and 100 percent donor cells!

I rented an apartment near the hospital. My husband's leave of absence from work had ended, so my oldest brother and sister-in-law became my caregivers. Wearing a mask and gloves, I walked the city streets and I set goals: First, I'd make it to the grocery store, then the children's clothing store, and then the cosmetics store. Finally, I walked to Bloomingdale's — a big accomplishment.

My third post-transplant bone marrow biopsy showed no sign of cancer so we had a big celebration. Physical therapy started next and helped me get stronger. Since then, I have continued an exercise routine to improve my stamina and strength.

My third "birthday" has passed, and I continue to be cancer free! I am able to run around with my daughters; my husband can do his work and travel for business. We enjoy all the things we did before my illness: seeing family and friends, eating out, going wherever we wish.

I have learned to appreciate the little things — taking a shower without getting exhausted, playing with my kids, and not worrying about my counts. I try to find humor in things and laugh a lot. I don't take my health for granted. I remember to let people know I love them and how much I appreciate them. I always try to live in the moment. And what a lovely moment this is.



ASK THE PROFESSIONAL

How to Care for and Treat Your Scars

By Dr. Anthony Rossi

Anthony Rossi is a board-certified dermatologist at MSK.

What is a scar?

A scar is the healing response that your body creates after surgery or trauma and is a natural part of wound healing. A scar will go through stages. Many times patients say that their scar itches or feels firm and tight, which are all expected as the wound heals. A scar is not fully mature until about one year after the time of surgery.

Some individuals may form irregular scars called keloids or hypertrophic scars. These are scars that grow beyond the limits of the surgical site and that can continue to grow and cause pain, itch, or feel firm. If you are prone to these types of scars, let your surgeon know, as there are ways to prevent them from forming after surgery.

Other types of cutaneous scars include changes to your skin after radiation treatment or other medical treatment. After radiation, the skin can become tough and many blood vessels, called telangiectasias, can grow in the area. This is called radiation dermatitis. Some patients liken this to a surgical scar and may seek treatment for it. Even the tiny tattoo marks that are placed to guide radiation can eventually

be removed once treatment has finished.

Also, for some patients who may have to take corticosteroids during their treatment, the skin may develop stretch marks, called striae. These can occur in many areas over the body and may appear red in color or eventually turn lighter compared to the surrounding skin.

How do I care for a scar?

After the sutures (stitches) are removed from the skin, the surgical scar is still healing and is in the remodeling phase. At this time, the collagen in the skin is being reorganized. The wound is still weak, and it is important not to put too much stress on it. This includes not lifting too much weight or doing excessive exercises depending on where the wound is.

In the early weeks of wound healing, it is important to keep your scar protected from the sun and UV light exposure, as this can cause scars to get darker or hyperpigmented. It is also important to keep the area clean and well moisturized, with either Vaseline or other bland emollients, to allow the wound to fully heal.

Can I improve the appearance of a scar once it heals?

Scars can sometimes be an emotional reminder of a previous illness but there are many options for treating their appearance. Most scars, if given enough time, will heal well and flatten nicely on their own. If this is not the case, there are topical creams as well as lasers that can be used to even out the color as well as the texture of the scar. Additionally, injections of steroids can be used to help flatten scars. Combination therapy is also ideal for treating scars. Depending on what type of scar you have, a combination of lasers, injections, and topical therapies may work best.

For people who have experienced radiation-induced skin changes, after radiation for breast or head and neck cancers, for example, a certain laser can help remove the blood vessels that form. Similarly, for patients who have experienced stretch marks after long-term treatment with oral steroids, there's a laser that can help improve the quality and texture of the skin.

As always, it is important to speak with both your oncologist and your dermatologist about the best treatments for your skin.



Running from Empty

By Lori Westerhold

Lori Westerhold completed breast cancer treatment at MSK in June 2014. She recently celebrated her 31st wedding anniversary. She lives in suburban New Jersey with her husband, the youngest of her four children, and two crazy Jack Russell terriers, Maeve and Jasper. She participates in Cycle for Survival and enjoys cooking, reading, yoga, Pilates, and if forced to admit it, maybe even running.

I'm not a runner. I've always eschewed all things running, passing up the treadmill for the elliptical, preferring a brisk walk to a run. But when I felt my fitness routine had hit a plateau, I took the advice of my daughter and downloaded an app called C25K. The app is an eight-week running program that takes you from being a couch potato to being able to run a 5K. I was diligent and went out every other day as required.

I vividly remember completing Week 6, Day 3. That particular day required a two-mile run. It was a brisk, sunny, early fall day. My skin glistened with sweat. I remember what I was wearing and what the sky looked like. I was flying. I was exuberant. I told myself, "You are a runner!" But there was something else. Unbeknownst to anyone else but my husband, I had recently discovered a lump in my breast. So along with "You are a runner!" there was this: "You just ran two miles! You can't be sick! Look how healthy you are!"

Like a person who sustains a head trauma, it is the last real recollection I have before everything went dark. Three days later, when I learned I had breast cancer, my world imploded. Along with my troops, I mobilized. So many decisions were made, so much action taken, and the next thing I knew a year of my life had gone by. We all had our eyes on the prize, which, of course, was that I would survive. In the back of my head, though, there was another prize: I would get better and complete my running program.

Some days — most, in fact, during that year — I was in such a dark place physically, emotionally, and spiritually that I doubted I would ever emerge in one piece. The thought of ever running again seemed impossible. Yet I persevered with that nagging voice in my head urging me to shoot for my goal. I knew if I completed the eight weeks, it would be a turning point, a reclaiming of my life. I also knew the real milestone would be the day I would complete Week 6, Day 3 for the second time. On that day, I would revisit the incipient moment when one life ended and another began. I would be transported to the day I was still ignorant and blissful and cancer free. Except this time I would be better. Stronger, for having walked through the fire. That's what it would be like on that day I once again completed Week 6, Day 3.

Today was that day.

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 Anjoli Mammen at mammena@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

SPOTLIGHT ON Be the Match

By Melissa Sideroff

Be the Match Registry is the donor registry of the National Marrow Donor Program (NMDP). **Be the Match** offers the unique opportunity to help a patient by donating bone marrow, peripheral blood stem cells (PBSCs), or umbilical cord blood. Thousands of patients with leukemia, lymphoma, and other life-threatening immune disorders and blood diseases depend on this registry to find a match for stem cell transplant. A trained member of a patient's medical team can contact the NMDP to search the **Be the Match Registry** and other registries worldwide to access nearly 24.5 million donors and nearly 622,000 cord blood units. Below are commonly asked questions about the registry and the donation process.

Do all donations involve surgery?

The majority of donations do not involve surgery. Today, a patient's doctor most often requests a PBSC donation, which is nonsurgical. Umbilical cord blood is collected at the time of the delivery of a newborn baby and is also nonsurgical. A bone marrow donation is a surgical procedure. Whether they're giving PBSCs or bone marrow, donors typically go home the same day they donate.

Will my immune system be depleted?

Only 5 percent or less of a donor's marrow is needed for transplant purposes. The donor's immune system stays strong and the cells replace themselves within four to six weeks.

Who can join the Be the Match Registry?

Anyone between the ages of 18 and 60 who meets health guidelines and is willing to donate for any patient in need can join the registry. **Be the Match** focuses on recruiting new registry members between the ages of 18 and 44, since research has shown that younger donors provide the greatest chance for transplant success. Donors within this age bracket can join the registry at no cost. Donors aged 45 to 60 are asked to make a \$100 payment to cover the costs of joining. All donors are critical to transplant success and are considered for donation.

To learn more about joining the registry, visit www.bethematch.org or call 800-MARROW-2 (800-627-7692).

Source: www.bethematch.org



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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.

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
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