Bridges

CONNECTING CANCER SURVIVORS ■ VOL. 20, SPRING 2013

Living with Leukemia

by Bettye Whyte Jones

Born and raised in Milledgeville, Georgia, Bettye has been a resident of Brooklyn for the past 45 years. She was the lead female vocalist for an R&B band called Jimmy Glover and the Soul Twisters. She also won a Golden Poet Award at a poetry convention in Washington, DC.

A few years ago I started having terrible night sweats. I was also tired all the time and losing weight. Finally a little red flag went up in my head. I knew something had to be horribly wrong. Then one day I was watching *Good Morning America* and they had on basketball star Kareem Abdul-Jabbar who talked about having leukemia and about his symptoms. I said, "Oh my God, I have leukemia!" Because his symptoms were exactly the same as mine.

When I called Memorial Sloan-Kettering I was in tears. Thank God, the person I talked to was very nice and understanding and I was given an appointment to see an oncologist right away. It turned out I did have leukemia. I've been going to this same oncologist ever since. He explains everything to me about my disease. He also tells me to feel free to ask him any questions I have. How blessed I am to have a doctor who really cares. I trust him with my life.

Living with leukemia is not easy. One day I ran into a former coworker on the street and she asked me, "Are you bleaching your skin?" I'm thinking to myself, What an idiot, but I explained kindly, "No, the reason I'm so pale is because I have chronic myelogenous leukemia." Then she said, "Oh, I feel like such a fool. Please forgive me." I said, "Don't worry about it. You are already forgiven." Though I admit at the time I was a little hot under the collar.

When I was first diagnosed I thought my whole world had ended, that I would die and my sons would not have anyone because I am a single parent. Every Sunday my pastor would call and pray with me over the phone. That meant a lot. Religion to me is very important. Every night I set my alarm clock for 3:00 AM and get up for ten minutes to pray.

Right now I am in remission, but I still worry. What if the leukemia comes back? Meanwhile, I am truly enjoying

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Memorial Sloan-Kettering Cancer Center

Editorial

by Eileen F. Gould

By the time this editorial goes to press, it will be nearly four months since Hurricane Sandy roared into our area and devastated much of the Atlantic Seaboard. I am sure that for many, just as a cancer diagnosis, Hurricane Sandy will have lasting effects not just on the psyches of those affected but on their physical well-being.

Experiencing a natural disaster parallels enduring a cancer diagnosis. An analogy can be drawn that the height of the storm is like active treatment and recovery is essentially survivorship. Cancer survivors, like the coastal residents who are still affected by Sandy, continue to cope with the after effects of their "storm" and rebuild their lives long after the clinicians and professionals have released them.

Adjusting to a new "normal" can be a relentless, overwhelming, and all-too-consuming process that requires resilience. Resilience is defined as "the ability to recover readily from illness or adversity." Survivors are incredibly resilient while learning how to cope with hardship from an illness or even a natural disaster. The human spirit does bounce back.

Safety in Numbers

By Michal T. Winter

A true Brooklyn fighter, Michal has been battling ovarian cancer since 2006. She does this with the help of her husband, Warren, and her two wonderful daughters, Abigail and Liz. They are her greatest achievements.

Having been in and out of treatment for over five years, I recently received a lot of free time from Social Security and New York State disability. To fill this time, I participate in as many Gilda's Club events as possible, including exercise, health, and relaxation classes, and my favorite, arts and crafts. I like to bring my beads to the studio and sit and listen to the conversations while I make amateurish jewelry that I unload on my family.

Recently, a reaction to some meds caused tremendous pain and discomfort. Nevertheless, my need to get out of the house prompted me to attend arts and crafts. I apologized profusely for having arrived late. The minute I mentioned the reaction, I was met with incredible compassion. I could tell by their faces that these women had been in my shoes. We shared the experience of needing to remain on the couch because we hurt, the frustration of wasting the day.

Free time is wonderful; it helps get all those "projects" done. Unlimited vacation time makes it easy to plan a trip when family has time off. But it can be lonely during the week when it's me and the dog. He's cute and great for getting me out of the house, but not much of a conversationalist. My Gilda's Club classmates have come to terms with their free time; they fill as much of it as they can by taking classes or spending time with children and grandchildren close by. Ironically, I spent many of my "healthy" years working while the other mothers were home with their children. Now I am home and it seems the other mothers are working because their kids are grown. So many days it's me, the dog, the radio, and the occasional electronic recorded phone call from a local politician.

Recently, I met an old friend in the doctor's waiting room. We had met when I first got sick. She was very helpful and compassionate, answering questions and giving caring advice. I hadn't seen her in a while and was thrilled to catch up. In the time that had passed, we had to give up jobs due to medical constraints and we discussed the pros and cons of our situation.

Working offers a nice distraction, but you have to feel well enough and have the energy to carry out the day's duties. I am thankful for my connections with the women in my arts and crafts class. I experience comfort through being with people who can relate to my circumstance. I have loving family members who mean the world to me, but I don't want to tell them about every ache and pain. Especially after hearing about their fabulous European vacations or cruises to exotic islands — it can cause an inferiority complex!

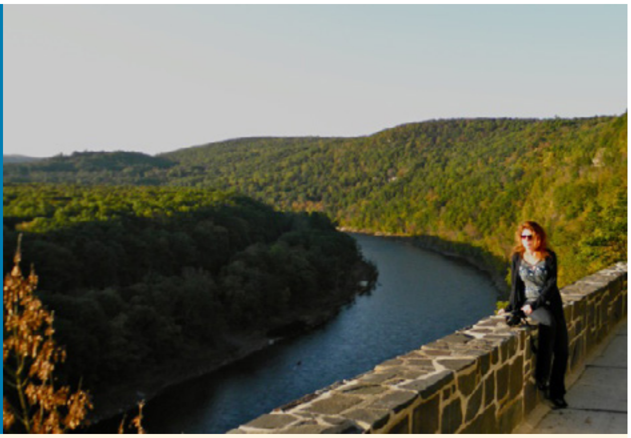
I enjoy my relationships with my healthy friends and family, but it is being with those kindred spirits who have shared experiences that enable me to feel safety in numbers.

Carry On

by Tracey Frezza

Tracey Frezza is a two-time survivor who celebrated her one-year anniversary of being cancer-free in the summer of 2012.

Born and raised in Queens, New York, Tracey currently resides on Long Island with her husband, Brian, and their two large dogs. Tracey's zest for life and her appreciation for the beauty in everyday life are portrayed in her photography.



I am a two-time survivor.

My first battle was at age 11 when I was diagnosed with a life-threatening illness called aplastic anemia. This is when the bone marrow, which is the factory that produces all of the blood cells, stops working. I was given a 50/50 chance of survival with a bone marrow transplant as the only option.

This would require my eight siblings (yes, eight!) to undergo blood tests to show whether their bone marrow matched mine. Tests determined that four of the eight were potential matches. Additional tests narrowed down the best match to my sister, Kerry. She would be my bone marrow donor.

I spent two months in the Reverse Isolation Unit of Memorial Hospital. It is a highly sterile environment, and visitors are required to surgically scrub their hands and wear protective gowns, gloves, and masks before entering the room.

I like to think of this time as the "living on the Upper East Side of Manhattan for two months" period of my life. My room had a million-dollar view of the East River. That was over 30 years ago.

Fast-forward to April 6, 2011: the beautiful day that I got ugly news. "Your biopsy shows cancer." I remember that day seeing a little girl getting off the school bus. She merrily skipped along. The expression on her face said it all. No worries. A complete contrast to how I was feeling at that moment. I wanted to be like that little girl — happy not sad.

The path led me back to Memorial Sloan-Kettering once again. My treatment consisted of radiation and chemotherapy. Due to the type of chemo I received, my hair was spared this time around. As many cancer patients can relate, losing your hair can be traumatic. Hair loss brings back a memorable event from my childhood.

Every summer, my neighborhood had a block party. The summer after my bone marrow transplant, I was 12 years old and quite happy to be on the road to recovery. My once long red hair, lost to chemotherapy, resembled that of a Chia Pet.

Sporting a white floppy hat, I anxiously awaited my turn to hop on one of the rides. The ride looked like a minibus with seats that went round and round.

"Step right up, it's your turn," said the man operating the ride. As I stepped forward, he said, "Take off your hat."

I took two steps back and shook my head and gestured "no, thanks." He explained that removing the hat was for safety reasons. The hat might blow off during the ride and get stuck in the tracks. Who was I to stand in the way of safety?

I held on to my little white hat for dear life and tried to bow out gracefully. He insisted that I get on the ride and grabbed the hat right off my head. The ride went round and round. Round and round. I hoped the fast motion of the ride would blur the view of my Chia Pet hair.

When the ride stopped, I put my hat back on my head and carried on.

This experience ended up being a very valuable lesson. In life, there will be difficult moments that we wish we could fast-forward through. Handle these moments with grace and carry on. In life, there will be awesome moments that we wish would never end. Carry these moments with you and handle them with grace.

Ask the Survivor:
How I Face Survivor's Guilt

By Paul Edelman, Jr.

Q *I recently lost a fellow cancer survivor and am experiencing survivor's guilt. Do you have any suggestions for coping with these feelings?*

A First, please let me express my sincerest sympathy for the loss of your friend.

Survivor's guilt is a common and often underestimated feeling experienced by both patients and caregivers. As a survivor or caregiver, we are expected to just be grateful and simply move on. Do not ask questions. But we do.

A year after my own treatment ended, I trained and participated in a peer-to-peer program with the American Cancer Society called "Cansurmount." The concept is to match survivors of cancer with patients who are struggling with their own diagnosis, treatment, or survival. My first patient was a 14-year-old girl who would eventually pass away from the same cancer that I had, leaving me to ask, "Why her and not me?"

As someone who was fortunate to have beaten the odds, it was not long before I found myself facing an unexpected and insurmountable wall of self-doubt, which I refer to as my survivor's guilt. Perhaps survivor's guilt is a way for our hearts and minds to remind us of where we came from, and what we have endured. The important thing to realize is that this feeling is often overwhelming, but can be alleviated.

With technology, I have been able to widen my experience and knowledge of cancer patients and survival. I have participated in Internet support groups for over 15 years and finally accept that with 22 years of survival behind me, I am a long-term survivor. Surviving also means that I have experienced loss. In just over a decade, I have said goodbye to well over 100 friends and relatives who were not able to achieve that remission. The question I still ask myself is always the same, "Why them and not me?"

But what gets me through each and every day is knowing that my survival mattered to those who have passed. My experiences inspired them just as theirs inspired me. There is no way to know the reasons that some survive and, sadly, others pass. The answer can be as simple as the one that comes from a parent when a child asks, "Why?" and the parent responds, "Just because." It is cruel and it hurts. It matters that you are here now and asking this question because at some point someone else will read your question when they are questioning their survival and know others have gone through a similar experience. Reach out for help. Support from others with personal experience or professional knowledge (like the staff of the MSKCC Counseling Center) is essential to help us understand that what we feel inside is common and expected, and can be overcome.

■ *Continued from page 1*

life and doing things I never did before. I've taken a course in acrylic painting. I appeared in a performing arts production where I sang my own gospel version of *If I Had a Hammer*. It has been a dream of mine to get a college degree. I did enroll in college once but had to drop out. Now I'm in a program at Kingsborough Community College in Brooklyn for adults fifty and over who want to continue their education.

Once I'm better I hope to become an MSKCC volunteer. I did help one patient already. A while back I was sitting in the ground-floor waiting area and a young lady next to me was on her cell phone screaming and yelling at her insurance company because they were refusing to pay for her medication. When she hung up, I said to her, "Listen to me! Go right back up to your doctor and ask him please to call your insurance company." About a half hour later there was a tap on my shoulder. It was the lady, this time with a big smile on her face. "Thank you, thank you, thank you," she said. "I did just what you said and it's all straightened out and the pharmacy is right now filling my prescription." And with that she bent down and gave me a big hug.

Ask the Professional:
MSKCC Executive Chef Pnina Peled

Q What changes have you made to the MSKCC cafeteria since coming to the hospital?

A I have implemented several changes to the cafeteria since becoming Executive Chef. We use fresh ingredients from local sources. Processed foods have been virtually eliminated, and we no longer use frozen vegetables. I have worked with a wellness nutritionist to include healthy options. We barely use any salt, and we now use extra-virgin olive oil. We also offer what we call a WISEPICK, which is a portioned meal composed of a protein, a veggie, and a grain. Every day, there is an interactive, made-to-order food station where you can mix and match ingredients. All salads and sandwiches in the Grab-n-Go section of the cafeteria have the nutritional info included. We are working with the New York City Department of Health's Healthy Hospital Initiative to meet new standards.

In addition to our culinary changes, we have worked with the MSKCC Green Team to reduce our impact on the environment. We now use biodegradable bowls and cups and regularly host a local farmers market.

For a healthy recipe from Chef Pnina, see the back cover.

Pnina Peled was born and raised in the restaurant business: Her father has owned and managed restaurants all her life. As an eight-year-old child, she would wake up at five o'clock on Saturday mornings to help him. She attended Peter Kump's New York Cooking School and went on to work at Becco and Eleven Madison Park before opening a restaurant with her father. In December 2009, Chef Peled made the transition from hospitality to healthcare. She hopes to help people in need, through food. She reads recipes and tries new dishes constantly, to continue learning her craft every day.

I have had issues with my taste buds since treatment. What foods might taste good?

Foods that are sour, bitter, or sweet may perk up your taste buds.

What are some of the flavorful and nutritious dishes served in the cafeteria?

Each day, through the Talent Management Program in the cafeteria, we have a Specialty Salad Section that offers two different selections. The grain, cheese, and legume vary daily. Our goal is to offer tasty, balanced meals.

What is your favorite energizing breakfast?

My favorite healthy breakfast is the protein-based "wellness" special, which is cooked turkey, egg whites, lettuce, and tomato on a hero.

My favorite comfort breakfast is Caribbean porridge, which is made with cornmeal, coconut milk, cinnamon, and nutmeg. I also like banana fritters. Some days we need comfort food.

I cannot eat large meals at one sitting. What dishes in the cafeteria do you recommend I try?

I recommend getting our specialty salad, a small homemade soup, and a roll. There is always a vegetarian soup option.

Andrea Guarino is a 52-year-old breast and liver cancer survivor who lives in Port Chester, New York. She teaches pre-school and directs the Pre-Kindergarten Academy in Port Chester. Andrea and her husband, Sandy, have a daughter, Juliette, son, Gregory, and son-in-law, Will.

What a Difference a Year Makes

By Andrea Guarino

As I pull my chocolate kiss cookies from the oven for my daughter's wedding shower, I do not take such a simple task for granted. In June 2011, I had serious doubts that I would be around for her July 2012 wedding. A simple blood test from an overdue physical initiated the whole saga. At that time, my liver enzymes were abnormally high. I had tests taken at a local hospital followed by visits with doctors who were clueless as to what might be causing the high count and were unable to refer me to someone more knowledgeable in the area of liver function.

Two weeks after receiving an endoscopic retrograde cholangiopancreatogram at Beth Israel Hospital, I was diagnosed with a carcinogenic tumor supposedly blocking my bile duct. I asked my breast surgeon, who had performed a lumpectomy in 2003 for DCIS, for guidance in selecting a physician. After eight years of having regular checkups with this excellent surgeon and compassionate gentleman, I felt secure in trusting his referral. Eventually, I ended up at Memorial Sloan-Kettering with Dr. K as my surgeon.

When I first met Dr. K in March 2011, I had good vibes. Dr. K seemed pretty cool. I learned that he had spent some of his earlier years growing up in the same area I did. I felt comfortable because he seemed very "down to earth." Besides being quite knowledgeable in his field, he seemed to be a caring individual, and he explained clearly, openly, and honestly what my situation involved. Since my tumor was slow growing and I really wanted to finish school in my position as a preschool director and teacher, he arranged for me to have my surgery over the summer as long as my every-six-weeks blood test results did not get worse.

My surgery was on July 6, 2011, at Memorial Hospital. During the long, complex surgery, the medical team found that I had two neuroendocrine tumors attached to my bile duct. It was an extremely rare situation.

I found it difficult to have a bile bag attached to me for close to 11 weeks during my recovery phase. One of Dr. K's main assistants demonstrated patience and kindness toward me during those weeks that I was getting frustrated with the bag. She would check in often and try to alleviate my worries and help me get through my ordeal.

One year later, I have two graduations to attend. My daughter received her Master of Science in Education from Hunter College, and my son an undergraduate degree from Stony Brook University. My preschool is relocating. I have my daughter's shower and wedding very soon. Most importantly, I am here. My doctor saved my life, and I will show my gratitude as long as I am on this earth.

So, folks, it is a no-brainer. Memorial Sloan-Kettering saved me — plain and simple. I think I will try to drop off some cookies to them, too!

Survivor Health Tip: Keep a Daily Food and Activity Diary

According to the National, Heart, Lung, and Blood Institute, keeping a record of your daily food intake and activity levels will give you and your healthcare provider a quick way to check your progress toward maintaining a healthy weight.

Resource Review:
VIRTUAL GROUPS

Virtual Groups offers live, online, interactive support groups and educational programs to Memorial Sloan-Kettering patients and their family members. For many reasons (including distance, the cost of travel, illness, family responsibilities, and work), it can be difficult to get to Memorial Sloan-Kettering to participate in patient programs. Virtual Groups offers a confidential, convenient, and cost-free method of getting involved. Patients and families have the opportunity to speak directly to each other while simultaneously benefiting from professionally led educational and supportive programs. All groups are facilitated by trained, professional Memorial Sloan-Kettering staff. We are pleased to announce that we recently opened several of our groups to the outside community as well.

To participate in a Virtual Groups program, all you need is a telephone and Internet access. Technological skill is not required.

Please go to www.mskcc.org/cancer-care/counseling-support/virtual-groups to learn more about our upcoming programs. You can also e-mail us at VirtualGroups@mskcc.org.

Gone But Not Forgotten

By Kristen Palmer

Kristen is 39 years old and lives with her husband, Russell, and son, Andrew, in Cortland Manor, New York. She works for Putnam/Northern Westchester BOCES as a teacher aide and is an aspiring writer. She just completed her first novel, "Always Has Been, Always Will Be." In her free time Kristen enjoys gardening, painting, and spending time with her family.

I was married on October 26, 2002, and began to suffer bronchitis-like symptoms six months later. A chest x-ray showed a shadow on my lung so I underwent a bronchoscopy. A specimen was sent to the lab, and then the waiting began. I received a call while at work and was told, "You have a fungus growing in your lung. That's what's obstructing your airway."

That doesn't sound so bad, I thought.

"However, underneath the fungus we found melanoma."

Hold up. Melanoma? Isn't that skin cancer? How can it be on my bronchial tube?

The weight of the news hit me hard. It was like I was dead already, lying in my coffin looking out at all my loved ones who came to say their final good-byes. I envisioned my son's sad little face. I wanted to reach out and comfort him, but I couldn't. I was dead. Wait, no, I wasn't dead, not yet. I picked myself up and went to Sloan-Kettering, the institution that would treat my cancer.

Treatment was a team effort. Out of necessity, my husband, Russ, became my manager. He scheduled appointments and arranged rides. He made sure I was in the right place at the right time, and he took off from work to be with me while I had my treatments.

My friends and family took care of my spiritual needs. I'm told I was being prayed for in Hebrew, English, Spanish, and German. I prayed to the Archangel Raphael, the patron saint of medicine and travelers, every morning, and hung a painting of Our Lady of Guadalupe in my home. I kept my faith in God and tried not to ask, "Why me?" It's not as hard as one may think when you're sharing the waiting room with a teenager.

After six courses of chemo, my medical oncologist extraordinaire told me that the tumor had shrunk and could be removed. My thoracic surgeon excised the tumor on my 30th birthday. She came to visit me during my recovery and conveyed that she had gotten it all. It was finally over.

But cancer is never over: It lingers constantly in the back of your mind. It's on TV, it's in pink ribbons and buttons and bracelets. It's in every benign headache, muscle ache, and cough you experience. I just want to forget. But I can't forget. So every day I put on my sunscreen and my stupid wide-brimmed hat and go about my day. (If one more person says, "Howdy Tex," I'm going to have a conniption.) Every night when I lay my head down to sleep, I thank God. Not for healing me, but for the wonderfully talented, inspirationally compassionate doctors and nurses at Memorial Sloan-Kettering. From the moment you walk through the doors you can be confident that you are not only in good hands but in God's hands.

Salad plated by Justin Evans, Chef de Cuisine

Harvest Salad

Simple-to-prepare recipe by Executive Chef Pnina Peled

Salad

Yield: Makes 4 servings

12 ounces mesclun greens
1 Gala apple, sliced
4 ounces dried cranberries
8 ounces red seedless grapes, cut in half
4 ounces crumbled blue cheese (or substitute goat cheese)
8 ounces crushed walnuts
Raspberry vinaigrette
(see recipe at right)

Divide greens on to four separate plates. Top with a few slices of apple, then sprinkle each plate with 1 ounce of cranberries, 2 ounces of grapes, 1 ounce of blue cheese, and 2 ounces of walnuts. Pour dressing on top and serve.

Raspberry Vinaigrette

Yield: Makes 4–6 servings

½ cup fresh or frozen raspberries, thawed
¼ cup extra-virgin olive oil
2 tablespoons fresh lemon juice
1 tablespoon honey
Kosher salt and freshly ground black pepper

Place all ingredients in a blender and puree until smooth.

Memorial Sloan-Kettering
Cancer Center

Bridges is a publication of the Memorial Sloan-Kettering Cancer Center Survivorship Initiative.
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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

PATIENT – TO – PATIENT

We are grateful for the support of our patients and family members. If you are a former patient or family member who has completed treatment please consider becoming a Patient-to-Patient Volunteer.

For more information, contact Jennifer Wang e-mail **patient2patient@mskcc.org.**

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

Visible Ink™

A one-on-one Writing Program for MSKCC 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.**