Bridges

CONNECTING CANCER SURVIVORS

VOL. 18, FALL 2012

Adjusting

By Karl G. Merchant

Karl Merchant received his bone marrow transplant two years ago and is currently living with his two dogs in Pennsylvania where he paints and writes. He also does some consulting in event planning and acquisition.

It was a day after my surgery in 2005 and I felt pretty good. My surgeon came into my room. "I have some bad news, Mr. Merchant. We looked at the cells of the mass we took out of you and they are cancerous." It was a rare form of acute myeloid leukemia. I decided to go to Memorial Sloan-Kettering for treatment. After chemotherapy my cancer went into remission. I went back to work and stayed in remission for four years. Then in 2009 the cancer came back with pneumonia. This time I would need a bone marrow transplant.

I am one of the most fortunate bone marrow candidates. Four matches (ten-out-of-ten criteria) were found. In less than two months my match was chosen and the transplant date was scheduled. On December 24, 2009, I received a T-cell-depleted peripheral blood stem cell transplant from a matched unrelated male donor. It was a simple procedure.

After the transplant I had no interest in food. The staff gently eased me back into an eating routine. With their encouragement I continued to get some exercise and a shower each day. The thing I disliked the most was social isolation. I regularly received platelets for clotting factor, had some problems with anti-nausea medicine, and slept a lot. My wife of 36 years, who died from breast cancer last year, came and stayed with me when she could. I was grateful that I recovered and was able to be her caregiver. There were some bumps in the road to recovery. They are not the same for everyone. I developed fluid in my pleural spaces. I had a recurrence of yellow jaundice and had another small case of pneumonia.

There are certain milestones I look back upon with fondness: eating a tuna fish sandwich without throwing up; walking two blocks to get a cup of coffee with-

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Memorial Sloan-Kettering Cancer Center

Editorial

by Eileen F. Gould

This past June was a very busy month at MSKCC. In exactly one week's time, I attended three very special and different events at the institution. First, on June 6, the Volunteer Recognition Ceremony took place and more than 450 volunteers attended and more than 100 volunteers were recognized for their dedication to serving patients. It was wonderful to see so many people being honored for giving their time and energy in such roles as visiting inpatients, delivering flowers, and assisting with patient recreation activities.

On June 7, the Sixth Annual Pediatric Convocation honored former and current pediatric patients graduating from high school or earning their GED. It was awesome to see so many young people persevering and moving forward with their lives.

Then on June 13, MSKCC held its National Survivorship Day celebration. More than 450 cancer survivors, their families and friends, and hospital staff heard the Oscar-winning actress Kathy Bates speak about her experience as a cancer survivor. Two MSKCC patient speakers also shared their thoughts, and later in the evening everyone gathered for a reception and information sessions. In reflection, it was truly amazing to attend so many wonderful events that both celebrated and honored cancer survivors here at MSKCC.

The current estimate of cancer survivors in the United States is said to be near 13.7 million and expected to grow to almost 18 million by the year 2022 according to the American Cancer Society and the National Cancer Institute. With the numbers of survivors increasing, it is even more important to continue to address both the medical and psychosocial issues we face.

Cancer survivorship is an ever-evolving story. We would like to hear from you, so please share your story by e-mailing us at bridges@mskcc.org.

50/50: Better Odds in Vegas

By Su Ciampa

Su Ciampa has written essays about arts and culture for ARTNews, Budget Living, Bust, Edible Brooklyn, Jane, Seventeen, *and* Time Out New York *as well as* Salon *and* Nerve.com.

Despite having known about the OMG! Cancer Summit for Young Adults since shortly after I went into remission for Ewing's sarcoma, it was not until the conference convened in Las Vegas this past March in its fifth iteration that I finally participated. There were some great sessions on everything from being newly diagnosed to post-treatment discussions about body image and sex. Nothing was off limits. There were parties in nightclubs and $1 margarita specials.

But I almost missed the one event I was most looking forward to during the whole conference: the midnight screening of the film *50/50* about a twentysomething man with a spinal tumor who is given even odds on his chance for survival.

Granted, I had seen the movie before. In a regular movie theater with a lay (read: ostensibly cancer-free) audience. The mood was tenuous during the movie's more dramatic and comic extremes. I went to the conference expecting to feel more connected to the movie through the audience of survivors at OMG!

But as the screening was at midnight and I was still on East Coast time, I had decided to take a pre-screening disco nap. I woke up a few minutes after midnight. Part of me wanted to stay in bed. But then I thought of what I might be missing out on. So I threw on some clothes and headed down to the venue.

When I got there, the doors were locked. Luckily, a security guard was passing and was kind enough to let me in. I was about 15 minutes late and the main character was just telling his parents about his diagnosis, Angelica Houston as the mother saying, "I'm moving in," without missing a beat.

It may have been the smallest gathering of any at the summit, but it was the most intimate. Throughout the movie, the audience reacted viscerally, laughing raucously at the absurdity of Seth Rogan, coming to tears when the main character freaks out in his friend's car the night before a surgery that may kill him or save his life, cheering and clapping when he tells his cheating ex-girlfriend to get off his porch and take her stuff with her, laughing again when he comes out of surgery high on morphine, and becoming quietly giddy when, still high on morphine, he tells his nubile young therapist (somewhat inappropriately) that someday he's going to make her pancakes. I could tell that I was not alone in seeing myself in this movie. Not just

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Who, Me? Support?

By Vivianne Dalpe Tait

Born in Timmins, Ontario, Canada, Vivianne became a US citizen in 1981. She lives in upstate New York with her husband, three daughters, and dog. She is now retired from a 29-year career in education.

"Hey Mom, I'm back. Who was that leaving the room?"

"Hi, honey. It was just those patient support people wanting to know if they can come see me. I said no, thanks. I don't need that kind of thing."

"Mom, do not ever let me hear you say no to them again. Support services at Sloan-Kettering are here to help us. They will make your recovery easier." The American Heritage Dictionary defines support as follows: v. 1. To bear the weight of. 2. To maintain in position; to hold up. 3. To be capable of bearing; withstand. 4. To keep from weakening or failing.

My cancer experience began on June 3, 2010. I did not feel well for a few days and went to see my primary care physician. She couldn't find anything wrong, but decided to do some blood work, just in case. By June 18, I was in MSKCC, diagnosed with acute lymphoblastic leukemia. I immediately began chemotherapy with the understanding that I was a good candidate for a bone marrow transplant. I was grateful to have my daughter beside me. At the time, she was completing her doctorate in immunology and was able to translate the baffling information about medicines and chemotherapy and the chances for long-term survival with a bone marrow transplant. The nurses told me that patient support services were there to help, but I decided that my daughter was all I needed.

Support services at MSKCC include counseling, physical therapy, massage, and yoga, to name a few. Keeping my daughter's words in mind, I agreed to have my feet massaged. Before long, I wanted my hands massaged too. Massage therapy did two things. I felt better physically, and more importantly, I no longer felt like an untouchable. The doctors and nurses are constantly after patients to exercise. They explained that the body needs movement to get better. My body needed to get ready for a bone marrow transplant and more chemotherapy. The first time the physical therapist came to my room I was eager to get started. But when the therapist told me he wanted to begin by timing how long it took for me to put my sock on, I was incredulous! He told me he would time me on his stopwatch. I leaned over and realized that my hands, leg, and foot were shaking so much I could not get the hand and foot to meet!! After a long time, I finally got the sock on. I was worn out.

The therapist said: "Your body has been overwhelmed with chemotherapy and you almost need to start all over again." I began to understand that his role was to keep me from weakening further.

Yoga therapy was a joy. Yoga in the hospital is not strenuous, but it does make your body and mind feel more relaxed and elastic.

I was most reluctant to have counseling. I was afraid of what I would learn about myself. After my bone marrow transplant, my brothers learned that my father was dying of cancer. I was so upset I asked to talk to a counselor. She so understood and helped me assimilate my father's death and my own frightening position. We became friendly and when I had to leave MSKCC and go to Hope Lodge post-transplant, she helped ready me for my adventure in recovery.

Everyone at MSKCC falls under the definitions for the word support. The kitchen staff does its utmost to serve good, healthy meals, and for bone marrow transplant patients they even offer tempting little delicacies. The maintenance staff supports the patients by keeping the facilities in top condition at all times. The nurses provide for physical and mental health by explaining everything and answering endless questions. The doctors are fabulous and bring expertise, experience, and compassion to their patients. But those who most embody all the meanings of support are your family. They suspend their lives to care for you; they give you faith and the spirit to move forward every day that you are undergoing treatment and every day through your recovery. Who, me? Support? You bet — all I can have and then some; support helps save your life.

Ask the Survivor: Fear of Recurrence

Q I have completed my treatment for cancer, but am still anxious about it returning. Do you have any recommendations for coping with fear of recurrence?

A Fear is a universal and very human emotion. As small children most of us were afraid of the dark or monsters under the bed, but all it took was Mom allowing a night-light in the room, or Dad crawling under the bed with a flashlight to ascertain that only one bedraggled teddy bear and a small pile of dust lived there.

Once we become cancer patients, however, monsters under the bed give way to a very concrete fear of recurrence. In the 32 years since I have had cancer, and the 24 I have served as a Patient-to-Patient volunteer at MSKCC meeting with patients, I have rarely met someone who has not expressed the fear of recurrence. When will the other shoe drop? How can I sleep at night knowing "it" (the cancer-monster) might come back? I like to reassure patients that this is a universal fear and nothing to be ashamed of. After all these years I still become nervous a month or so before my mammogram. The good thing is that I am no longer as nervous and frightened as I was years ago, and that trite as it may sound, time is a great healer. The longer you go without a recurrence, the more faith you have that a complete cure may be possible.

By Lorna Kettaneh

Lorna, who grew up in New York, received a bachelor's degree from Mount Holyoke College and a master's degree from Middlebury College. She is bilingual, French/English, and in her younger days she lived in Paris and also in Beirut, Lebanon. She has two grown daughters and four grandchildren. She has been working as a Patient-to-Patient volunteer at MSKCC for 24 years and also sits on the Patient Education Committee. She spends a great deal of time reading, writing, and visiting museums.

The proof lies in the ever-growing number of weeks, months, and years that you have been disease-free. None of us likes to go to the doctor or be subjected to multiple tests. However, there is a wonderful feeling afterwards, when the doctor tells you that you are fine, and that he/she does not want to see you for another six months, or one year. That visit also represents a forum where you can ask questions: What is this lump I noticed? Is it normal for me to be feeling this way? If it does return what can we do about it? Do the bruises I have indicate anything? The latter was one of my greatest fears six months after my surgery. I had convinced myself I had leukemia, until my doctor explained that I should remember that I had always had a tendency to bruise easily, and that with two very young children constantly running into me with their toys, strollers, etc., it was normal to have bruised legs!

We need to address our fears face-to-face: I know you are there, but also know that you will diminish with time. If I have a question about my health I will consult my physician. I will keep busy in my daily life so that I do not have time to brood constantly. If I feel I need professional help, I will seek it. And finally: There are days where you might win over me, and I shall cry, but I am strong and will use every means, perhaps not to banish you entirely from my life, but to allow us to adapt to each other, a kind of modus vivendi; yet ultimately I shall keep the upper hand!

Ask the Professional: Cancer and Fertility

Q I have completed my treatment for cancer and am wondering whether I will be able to have children in the future. What options are available to me to build a family when I am ready?

A Some types of chemotherapy and radiation can destroy a woman's eggs or impair sperm production in men. The effect on fertility depends on the type and dose of chemotherapy, the area of the body irradiated, and for women, the age when treatment was begun. Surgery can also affect fertility if reproductive structures are involved.

Most patients are recommended to wait at least one to two years after treatment before attempting to conceive. Ask your doctor how long you should wait. A fertility evaluation at that time may indicate the likelihood that you will be able to conceive naturally. Women can go to a reproductive endocrinologist to check hormone levels and have an ultrasound to view the ovaries and count the number of developing eggs. Men can have a semen analysis that reports the number of sperm and their motility (ability to swim). If the results indicate that it may be difficult to conceive naturally, there are a number of options to consider.

Joanne F. Kelvin, RN, MSN, AOCN

Joanne is a clinical nurse specialist who leads MSKCC's program in Fertility Preservation and Parenthood After Cancer Treatment

Women can undergo in vitro fertilization (IVF). This involves hormone injections to stimulate the ovaries, collection of mature eggs, fertilization of the eggs with sperm to create embryos, and transfer of the embryos into the uterus several days later. If you had the opportunity to freeze embryos before treatment, these can be thawed and transferred. If you froze eggs, these would be thawed, fertilized, and then transferred. Another option is to use donor eggs fertilized with your partner's sperm to create the embryos. For women who are unable to carry a pregnancy, the embryos can be transferred to the uterus of a gestational carrier. Women who have had treatment that may impair fertility are also at risk for early menopause. Even with monthly menstrual periods, they could lose fertility at an early age. If you are not yet ready to start a family but want children in the future, you could consider undergoing IVF and freezing eggs or embryos for later use if you need them.

Men who have no sperm in their semen and had the opportunity to bank sperm before treatment can have the stored vials thawed and used for IVF with their partner. Men who did not bank sperm can go to a reproductive urologist to consider testicular sperm extraction. This is a minor surgical procedure in which pieces of testicular tissue are removed to look for sperm that may be present in very small numbers. Another option is to use donor sperm to fertilize your partner's eggs.

Adoption is another way to build a family. Having a history of cancer does not prevent you from being able to adopt as long as you are healthy and have been cancer-free for a certain number of years. Thinking about all these options may be overwhelming at first. Keep in mind that many people have gone through this before you and have been successful in building a family after cancer treatment. To learn more, go to www.mskcc.org/cancer-care/survivorship/fertility-parenthood-0. Here you will find links to our patient education material and other resources for information and support.

My Mission

By John Patrick Thomas

John Patrick (Jay) Thomas is a four-time cancer survivor who lives with his family in Mt. Pleasant, South Carolina. Jay turned to the teaching profession after his life-threatening bout with bone cancer. He has taught at Charleston Southern University, Southern Wesleyan University, and more recently at West Ashley High School. He has also traveled as a missionary.

As I looked up at the building, I realized that I had passed it hundreds of times as I traversed the city in my mergers and acquisition business duties, never giving it a second thought. Today was different — very different. You see, during a routine physical a lump was found in my throat, and it was determined that I needed to see a specialist. I had a friend who just went through cancer treatment and suggested that I go to Memorial Sloan-Kettering Cancer Center. I took her advice. My wife and I stood before MSKCC wondering what the appointment would hold. I was nervous and anxious, as I was only 29 years old and had never been sick a day in my life.

As I recall, the waiting area was warm and comforting, although I felt cold and somewhat panicky inside. The hospital staff had received my documentation from my primary care physician and was well aware of my situation. A biopsy would be needed of the nodule in my throat, which was about the size of a peppercorn. To make a long story short, the biopsy came back positive for papillary carcinoma of the thyroid gland. Not the news I was expecting to hear. If you are going to have thyroid cancer, this is the least aggressive form of the several that are out there. The treatment protocol does not call for radiation or chemotherapy, but surgery. Surgery didn't sound too bad, except that it would be my throat that they would be cutting!

The friend who had suggested I go to MSKCC had had the same surgery there and said that all went well for her. She actually had a plastic surgeon on hand to do the closing, so as to minimize the potential scarring. Having her to talk to throughout the process was a great help in knowing what to expect. My surgery went off without a hitch as well. I let the general surgeon close my wound, as opposed to a plastic surgeon. Must be a guy thing!

As it turns out, this was not my last experience with cancer. I later learned that from somewhere along the family genetic line I got a faulty *p53* gene, which has something to do with turning on and off cancer activity in cells. As I aged, I was diagnosed with two melanomas; both were caught in time and were removed with surgery. No need for any radiation or chemotherapy.

Then, havoc struck again. My family and I had moved to Charleston, South Carolina. As I was getting on a ride at the fair with my daughter, the act of putting my arm around her snapped the bone in my right arm. I was in such pain that I flew off the ride before it started, without any thought of my daughter, who was only five at the time. The doctors had determined that it was a pathological fracture, and after much testing came up with a diagnosis of Ewing's sarcoma, a primary bone cancer.

I am now in remission from the bone cancer, but lost the use of my right arm. I was looking for hope during that journey, but it was difficult to find in those days. I am thankful for publications like the *Bridges* newsletter that let us share our stories and inspire us with messages of hope from other survivors

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because I had a spinal cancer as well, or because I saw one relationship end and another begin during the course of my treatment and recovery, but because of the broader truth of what it is like to be young and to know that, in the words of Mos Def, for you and me life is not promised. And to feel in a room of survivors that you managed to persevere against the odds, whether you have no evidence of disease or are living with cancer. Not everyone ultimately survives, but we have each other and that makes all the difference.

Transformation

By Diane Ippolito

Diane is a 45-year-old licensed massage therapist who also holds a bachelor's degree in business administration. She lives in Coconut Creek, Florida, and her motto is "The only limitations in life are the ones we place upon ourselves."

My story is far from a simple one, but it is one of transformation. I'm 44 years old and a cancer survivor twice over. In 1988, I was diagnosed with Hodgkin lymphoma. I was 20 at the time and about to enter my senior year of college. Thankfully, I had an amazing support system and completed my senior year with honors. My doctors wanted me to postpone my life and concentrate on the chemo and radiation treatments, but I knew how important it was to continue my life and to stay positive. In the end, I was asked to give our commencement speech at graduation and in it I tried to convey how grateful I was to be in remission.

All was well until 1998. The treatments I had received almost ten years earlier had affected my autoimmune system. Within ten months, I weighed 85 pounds, was being tube fed, and suffered seizures, severe neuropathy, orthostatic hypotension, and horrible irritable bowel syndrome. In a last-ditch effort, I was flown to the Mayo Clinic in Rochester, Minnesota. My mom was told to prepare for the worst. My dad came with me and we stayed there for two weeks while the doctors tried to figure out why my organs were shutting down so rapidly. No one wanted to admit that the chemo and radiation could be at the root of my illness. So Dad and I flew back to Florida with little hope.

My neurologist at the time put me on an immune gamma globulin cocktail that allowed my body to stop attacking itself long enough to begin healing. It took a couple of years for it to make a significant difference and I was wheelchair and bedbound for five years. I had daily seizures, wore diapers, and had no life. The pain was intense, and a heavy narcotic regime was in place.

Diane with her parents, Antoinette and Arsenio (Sammy) Ippolito

In 2005, I started rehabilitating myself out of that wheelchair, even though I was told I'd never walk again. In 2006, I noticed a lesion on my tongue that turned out to be cancerous. I don't smoke, so my conclusion was that it was caused by the radiation I received in '88. I had a portion of my tongue removed soon after, which was probably the most painful surgery thus far. Depression took over my life and I considered suicide to end my suffering. Thank God for my family and friends who helped me down the path of recovery!

Finally, in 2007 I admitted myself into a 28-day rehab program. During that month's stay I recognized how dangerous it is to self-medicate. Thankfully, I've been in recovery since then. I now manage my pain in holistic ways: chiropractic, herbs and supplements, massage, meditation. I have too much to live for and I'm trying to rebuild my life despite my physical limitations. It's far from easy, but the alternative is not an option!

Today, I'm diligent in my doctor visits, scans, etc. If I'm ever faced with a serious illness again, I know I'll be able to deal with it by the grace of God and my family. My advice would be to always have faith and never lose hope. The rest will fall into place.

If you are ever having suicidal thoughts, please contact your physician or go to the nearest emergency room. Also, the national suicide hotline is 800-273-TALK.

Resource Review: Audio Biography Project

Following the success of MSKCC's pilot collaboration with StoryCorps in the spring of 2011, the Department of Volunteer Resources is pleased to announce the launch of MSKCC's Audio Biography Project (AB Project). The mission of the AB Project will be to record the stories of MSKCC's community. Through the collaboration with StoryCorps we saw the meaning that recording one's story can bring to our patient population and we are now excited to extend this opportunity to the entire MSKCC community, which includes patients, caregivers, and staff members. This program is a great way to celebrate and share personal narratives with your loved ones. Volunteer staff are trained and prepared to record these 30-minute interviews. Participants should allot 45 minutes for the entire recording process. Participants will receive a copy of the interview to share with friends and family.

Recordings will take place at Bendheim Integrative Medicine Center, 1429 First Avenue (at 74 Street), on Tuesdays from 10:00 to 1:00 PM and on Thursdays from 2:00 to 5:00 PM. To schedule your own recording please call 212-639-5980.

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out having to sit down and take a break; returning to my home in Pennsylvania.

As of this writing it has been 28 months since my transplant. I have dietary precautions to which I must adhere. I go to the gym three days a week. I have taken up oil painting and writing as serious hobbies. I serve as a Patient-to-Patient volunteer for the hospital, speaking with patients who are considering a bone marrow transplant.

The constant monitoring by my MSKCC medical team has been most helpful during my recovery. Adjusting to a less active life requires vigilance. My immune system has not fully recovered and I am still waiting for the time when I can receive my immunizations. I am adjusting to the fact that recovery takes time. I feel stronger mentally in facing challenges and I value my relationships with family and friends even more, which I didn't think was possible. I feel humble and honored that I have been given this gift of new life.

If you are considering a bone marrow transplant, here is what I have learned:

a) The decision is personal. Whatever choice you make will be the correct one.

b) The recovery process may include bumps in the road and requires patience.

c) A positive mental attitude is very important.

d) Adhere to your medical team's advice.

e) Live life every day.

Memorial Sloan-Kettering
Cancer Center

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Bridges is available at www.mskcc.org/bridges.

If you would like to connect with other survivors through the Resources for Life After Cancer Program, 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 e-mail patient2patient@mskcc.org.

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