

The Hidden Blessing in My Disease

Diane M. Macbeth

I am a 55-year-old Staten Island resident employed as a sales manager for a shipping company, Perfect Air and Sea, located in Jamaica, New York. I am an avid wine maker and a frequent traveler to Italy for la dolce vita (“the sweet life”). I have an appreciation for the arts and am President of the Board of Directors for Colonial Gardens Corporation LLC. My life changed in November 2010 when I was diagnosed with stage IV colon cancer. I have always believed in “the glass is half full” philosophy and will continue to do so!

Damn, why doesn't this back ache and lousy feeling go away? I have a date with Caravaggio in the Uffizi in Florence in six weeks! Must be the exercise and dieting I've been doing, must be my gallbladder — after all it can start acting up when you start dieting, right? Might as well go to the doctor. I'll get some medicine for the gallbladder and I'll be able to

waltz through Florence and Venice and have a grand time.

“Hi Doctor, thanks for the call. How did everything workout with the ultrasound? Enlarged liver with spots?”

October 18, 2010, the day my life changed: Funeral plans ran through my shocked brain and I was shaking like

a loose shingle in a tornado. CAT scan. OK, let's not think the worst. “I'm so sorry, Diane. You have a tumor in your colon.” More definitive funeral plans running through my head, more shaking. Colonoscopy, OK, I will finally go.

November 18, 2010: “I'm sorry to advise you, but the results came back positive. You do have colon cancer and it has metastases to the liver.” Great early birthday present!

OK, I'm a little more prepared and less shocked. I know I have God on my side and have always had a positive outlook on life. Hey, this must be an early stage because I had my annual physical in March, seven months ago, and I was fine.

Stage 4, Stage 4? TKO on that one. “It's not the optimum, but you can beat it.” OK, I can deal with this. The internist's optimistic and encouraging response gave me a much-needed shot of hope. This combined with my strong faith in God will lead me into my battle. Another bump in the road of life.

The disease, while scary and life changing, has also brought to me, and I'm sure to other cancer patients, some hidden benefits. I'm able to look at the

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Memorial Sloan-Kettering
Cancer Center



Dan Barry, 53, is a national columnist for The New York Times. He has been a patient/client of Memorial Sloan-Kettering since the summer of 1999. He

has written three books, including “Pull Me Up: A Memoir,” which in part discusses his experience with cancer. It was published in April 2004; two months later, he had a recurrence.

Somewhere in my house are photographs from Christmases past that draw the eye not to the wrapped presents or shimmering tree, but to a spectral figure folded into the living-room couch. Pale, bald, and only half-smiling, this is the ghost of chemo Christmas. Me.

Looking at those photographs now, I wonder: What was I thinking? How did I function? How did I manage that half smile?

In the Decembers of 1999 and 2004, my Christmas tree might as well have been a garland-adorned IV pole. Those years were so focused on cancer that holiday gatherings with family came as an intrusion upon my dark and worried meditations. Let’s just say that I was in no mood to wassail.

For the first grim go-around, a brutal chemo-and-radiation regimen had ended shortly before Christmas. Dr. P., my gifted, compassionate, and no-nonsense chemotherapist at Memorial Sloan-Kettering, recommended that my wife and I enjoy the holidays with our two-year-old daughter, and that I have the all-important CT scan after New Year’s Day.

With the question of my continuance temporarily set aside, we attempted a normal Christmas. Instead, everything I did, from hanging an ornament to biting a holiday cookie, carried the faint sense that it might be my last time doing so. Though trite to say, I became acutely aware of the wonder in the mundane.

January brought me a blessedly clean scan. The tentative all-clear would grant us four complacent years of life’s small irritations and great joys, especially the birth of a second daughter. But a devastating recurrence returned us to days defined by dread, and filled me with the foolish notion that I had tempted the fates by daring to write about my cancer-free reprieve in *The New York Times* and in a book.

Once again, Christmas followed several months of chemotherapy at Memorial Sloan-Kettering. Once again, Dr. P.,

along with Dr. B., that greatest of thoracic surgeons, recommended that we enjoy the holidays before I, um, have my esophagus removed. Once again, every bite of every cookie – mattered.

Five Christmases have come and gone since I opened my eyes in the hospital recovery room to see my wife giving me the nod. Those Christmases have provided more family photographs, including some in which I am smiling and fully in the moment.

But I will never throw away my chemo-Christmas images; in fact, I cherish them. They reflect my wondrous continuance, made possible by Dr. P., Dr. B, and so many others at Memorial Sloan-Kettering, from the radiation technologists who treated me with respect to the custodians who mopped my hospital room’s floor.

And so I raise this ordinary, extraordinary holiday cookie in a toast:

To them. To you. To us.

If you are interested in submitting your story or have suggestions for newsletter content, please e-mail bridges@mskcc.org.

I wish I had...



Shared by survivors at the 2011 MSKCC Survivorship Celebration

- A million dollars to give to MSKCC!
- Paid more attention to my body
- Not been so worried about chemo
- An ultrasound when I described the symptoms six years before being diagnosed
- Known that help was available for the asking, but no one told me to ask

The Ninth Floor — Sloan Kettering's Pediatric Waiting Room

By Molly Bagwell Santa Croce

Molly's teenage daughter was treated for a rare ovarian germ cell tumor at MSKCC in the fall of 2010. She lives in upstate New York with her husband and four children.



Sitting in the waiting room on the ninth floor of Memorial Sloan-Kettering is a unique experience. Each time I enter, I take a breath to prepare myself for what I will see there. I lock in a tiny smile, a sign of encouragement for the other parents here today. We support each other with our eyes. I understand, you do not have to explain.

Every day here is like an MRI — a cross section of children and their families in different phases of their cancer journey. Some are visibly ill, lying down with a blanket and Mom's arm to protect them. Some look odd, with swollen chipmunk cheeks from medications. Some just look tired. Some come in wheelchairs, strollers, wagons. Some speak Spanish, Russian, French. Some wear the traditional dress of their native countries. Cancer is not prejudiced.

Other children don't look sick at all. Maybe they are here for routine scans, blood work, or their yearly checkup.

Some are here for the first time. You can tell because both Mom and Dad are with them (and they have hair). Dad is dressed in a business suit, ready to return to his high-powered job, Mom is dressed in her best jeans and a blazer. I see Mom looking around the waiting room with terror, terror that she camouflages with a little smile and small talk. She steals worried glances at her son and I know what she is thinking: My son doesn't belong here. I watch as the family goes into the doctor's office, and know that when they come out, their lives will be changed forever. I feel sad, but in a strange way, privileged, to witness this most important moment in their lives. I hope my quiet, desperate attempts to convey understanding and encouragement are remembered.

We are now at a different phase. The post-treatment phase. The waiting game. My daughter looks and feels healthy. I notice others in the waiting room sneaking looks at her. Their faces relax a tiny bit when they see her. SHE had cancer, and she

looks great. There is a light at the end of the tunnel. For us, it was not a very long tunnel, but for others, it is long, dark, and scary, with many twists and turns. The expertise of wonderful doctors, the love and support of family and friends, and the kindness of strangers (never forgotten!) will guide them on their way. My heart breaks for all of them.

I read a great quote last night: "There are few things more liberating than having your worst fear realized." All of us parents on the ninth floor understand. Once your child has cancer, there is nothing left to fear. So we are all living, living the best we can. My daughter, by the grace of God, is healthy! And so we push forward, never looking back. But part of my heart will always be on the ninth floor. I hope its life force will surround and protect all those who enter there.

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blessings that the disease has brought to me (sounds crazy but it's true).

I never knew that I had so many people who loved and cared about my well-being besides my family. My disease has brought together estranged friends, friends I had lost contact with over the years. I look at each day as a precious gift and have learned the true value of love and caring. More importantly it has shown me what is most important in life: kindness, patience, compassion. People are praying for my recovery from Brooklyn to Los Angeles!

I have also conducted a much-needed reevaluation of my life. I appreciate the beauty of each day; I am less quick to judge. I realize now that my high-stress job that provided a nice lifestyle really wasn't worth it. My eating habits also needed to be evaluated; perhaps that extra cannoli wasn't such a good idea after all.

Now on the road to recovery, I am eating the wholesome foods the doctor has recommended and exercising, and I have been told I am looking better than I had before. My life has taken a turn and I believe it is for the better. I have been blessed by my tragedy.

My wish is to be able to provide strength, support, and encouragement to those with the disease who perhaps aren't able to see the beauty of everyday life, and aren't at that point of hope and optimism. Tomorrow is promised to no one, and while I pray and trust in God, I'll do my part and count my blessings and forge ahead with a positive and determined attitude. My wish for you all is a restoration of health and an appreciation for the good things life has to offer.

I want to extend a special thanks to my doctor and his team for their dedication, kindness, and professionalism. Thank you from the bottom of my heart.

Message of Hope

By Richard Deutsch

I am a 58-year-old software consultant who has resided off and on in Long Beach, NY, for the past 50 years. I live there with my wife of 28 years, Kathy, and my two children, Brian 25, and Kristen, 21. Diagnosed with a stage IV glioblastoma in July of 2005, I'm happy to report that I'm free of any disease and looking forward to the future.



Six years ago, I was diagnosed with stage IV glioblastoma brain cancer after ignoring subtle symptoms for ten months.

Initially, I saw floaters that resembled the MS logo on a PC! Next, random musical notes appeared. I was unable to identify certain words, which made reading and writing difficult. I suffered searing headaches. Still, I remained convinced I wasn't in any real danger. Then, I had two minor car accidents. After the second, I barely could stand up. I stumbled home and stayed in bed.

Surgery removed a golf-ball-size tumor from my brain. Two weeks later, the surgeon announced that the life expectancy for patients with this disease was ten to 14 months. The stress on my wife and teenage children was enormous. Mortgage, college tuition, bills, and future employment were all concerns. I was 52 years old; would I make it to 53? I was fortunate to be treated at Memorial Sloan-Kettering, where I was placed in a clinical trial featuring a stronger dose of the standard chemotherapy (Temodar). The chemo compromised the quality of my life.

Six months later, I was stunned to see the visual floaters again. The tumor

had reappeared. This news was terribly distressing, but I was enrolled in a new clinical trial of Avastin. Stuningly, this new drug not only wiped out my tumor in one month, but did so without noxious side effects.

Over the next three-plus years, treatments of Avastin came every two weeks, followed by tests. The tumor destroyed the peripheral vision in my right eye, making driving too dangerous. Minor "sticking" headaches and focal seizures would come and go. I was able to work from home as a software consultant, help out with the housework, attend most of my children's milestones, and generally forge ahead with one eye in the rearview mirror. In May 2009, the FDA approved Avastin. Due to a lack of long-term data on the drug, the doctor felt this was an ideal time to exit the treatment, knowing my insurance provider would cover the drug in the event of a recurrence.

Things went well for six months. Then, in December 2009, an MRI exposed a tiny white line where my original surgery took place. The cancer was back. The tumor was eradicated, again with Avastin. One year later, I'm still tumor free and all my vital signs are excellent. I can still work and function. In July

of 2011, I will be celebrating my sixth year of life since I stumbled into the emergency room. Brain tumors remain incurable for now, but they can be held in abeyance for long periods of time. I am living proof.

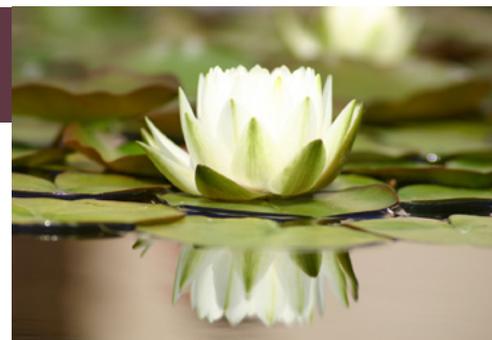
I meditate every morning (good for the soul), eat as healthily as possible (good for the stomach), exercise regularly (good for shrinking the stomach), and should somebody offer me a job opportunity, I'm ready. Both the National Brain Tumor Society (www.braintumor.org) and Have-A-Chance organization (www.haveachance.org) sponsor walk-a-thons every year where people can interact with others who share a similar experience.

Hopefully, my new schedule will stretch the treatments out far enough so that they retain their effectiveness without damaging my health. Beyond that, only Father Time holds the answers. For many, Avastin is not an option, but there are plenty of reasons for brain tumor patients to be positive. New drugs are being tested every day. I may not get a chance to realize all these medical advancements during my lifetime but our children should benefit tremendously from the groundwork we are laying today.

One line coping strategies:

Shared by survivors at the 2011 MSKCC Survivorship Celebration

- Keep calm and carry on
- Tomorrow will be better than today
- Being creative and feeling useful



Surviving SNUC

By David L. Schlossberg

David Schlossberg is the managing director of Wolff & Samson and practices in the firm's Trusts and Estates Group. He and his wife, Robyn, have been married for 33 years, and they have two children, Dana and Adam.

One Friday evening in May, 2008, during my typical ten-minute commute home from work, I suddenly experienced double vision. My immediate reaction was fear that I would not get home safely. Fortunately, I made it home without incident, but my thoughts turned to the cause behind the double vision.

While everyone reacts differently, my personality is such that I respond immediately to a problem, especially a medical one. In this particular case, urgency most likely saved my life. Over the course of two weeks, I met with several doctors, took numerous tests and had a biopsy before I ended up at Memorial Sloan-Kettering. As I was going through these tests, the thought of cancer never crossed my mind. The reason was simple. Six months earlier I experienced sinus headaches, so my general practitioner sent me for an MRI and the results were negative.

My first day at Sloan-Kettering was a bit of a whirlwind. I met with a team of doctors: Dr. P., an oncologist of head and neck cancer, Dr. W., a radiation oncologist, and Dr. K., the surgeon. After a full day of testing, Dr. P. informed me that I had a rare form of cancer commonly called "SNUC" (Sinonasal Undifferentiated Carcinoma). My team of doctors recommended that I start a regimen of chemotherapy and radiation the next morning. In their opinion surgery was too risky due to the size of the tumor and its proximity to the optic nerve. There was a real concern that the surgery might result in blindness.

Even though that first day was a blur, I do recall asking Dr. P. two questions: 1) Is it really possible that the tumor had grown to such proportions in less than six months? and 2) What is my long-term prognosis?

Dr. P. said it was truly impossible to address my long-term prognosis due to the rarity of the cancer.

What I quickly learned was SNUC is an extremely rare and aggressive form of cancer, so the tumor often grows to such size in a short period of time. As for my prognosis, Dr. P. said it was truly impossible to address my long-term prognosis due to the rarity of the cancer. Simply put, there were too few cases to fairly answer my question.

The next day, I started my journey at Memorial Sloan-Kettering with three days of chemotherapy followed by 18 days off to recover from the treatment. In the course of approximately three months, this process was repeated four more times. My perception prior to these treatments was one of great apprehension and concern. To my surprise, except for days when I had little energy, my chemotherapy experience was for the most part very manageable. When I reached the point where I would transition from chemo to radiation, I truly believed the worst was over. Unfortunately, my struggles were just beginning.

For the duration of six weeks, I received radiation to my head and neck five days a week. Although the process was fairly easy, I soon learned that the side effects would be difficult to manage given the location of the tumor and where the radiation was targeting. Within a week of beginning radiation, I had difficulty swallowing and everything I ate or drank tasted very metallic. Due to these issues, I lost almost 40 pounds and experienced regular bouts of dehydration. Worse yet, I spent almost 30 days in the hospital.

While this time in my life was extremely challenging, I was always comforted by the fact that the treatments were working. By the winter of 2008, all remnants of cancer cells had disappeared. I remember feeling incredibly relieved and overjoyed when Dr. P. informed me that I was cancer-free. It is now three years later, my hair has grown back, I've gained back weight (and then some), and most importantly I remain cancer-free.

Upon reflection, I have two very clear observations of my cancer experience. The members of my medical team at Memorial Sloan-Kettering, headed by Dr. P., were consummate professionals who always made me feel as if they wanted to win this battle as much as I did, and the love and encouragement from my family and friends was so instrumental in getting me through this difficult period in my life.



Searching for My Donor in a Subway Car

By Duane Bailey-Castro

A committee member and contributor to Bridges, Duane Bailey-Castro is a three-time survivor of Hodgkin lymphoma and the recipient of two stem cell transplants. He is a teacher in New York City.

During my morning commute to work, I look at the other people in the crowded subway car. Some are catching up on their sleep. Others are reading. Many avoid eye contact fixated by their iPod or smartphone. Others appear guarded. One of these strangers, I tell myself, just might be the nameless donor who saved my life.

Together aboard this downtown-bound subway car are the curious and the ordinary, white-collar and blue-collar, old and young, healthy and frail, the beautiful and the ugly, the slim and the overweight. I hear various accents and languages, notice symbols of different faiths, and see a spectrum of skin-tones. There are so many differences, a rainbow of riches. And yet, for a moment I feel oddly alone in the midst of so many. I feel strange — like a rare protected species — as I wonder how many others in this very car might have paused amidst the morning rush to reflect upon the beautiful bounty that is us and connects us all. I surely cannot be the only one.

Bombarded continuously by the 24-hour news cycle of debt and political dysfunction, terrorism and war, my morning contemplations feel somewhat academic, even childlike. The anxiety, insensitivity, sadness, and fear that is expressed by some of my fellow New Yorkers might be a reflection of their own struggles in this uncertain and confusing time. When

left unchecked, however, too much energy spent focusing on the wrongs of our world will make us miss out on the innate goodness and countless opportunities that are right in front of us. As I look around the car wondering if one of these unknown faces is that of my donor, I am reminded of this and refreshed as I prepare for the day ahead.

In August 2007, I became the fortunate recipient of an allogeneic (unrelated donor) stem cell transplant, hoping to turn the page on Hodgkin lymphoma once and for all after a third diagnosis. Four years later, I remain cancer-free. While my amazing medical team along with my family and countless friends are integral parts of this story, my donor is my hero. This stranger saved my life. It is expected that those closest to you will be there when needed, but a stranger? What inspired him to join the National Bone Marrow Program registry as a potential donor in the first place? I wonder. When he received the call that he was a match for someone, what compelled him to follow through? He could have declined. He did not know me or anything about me and had no obligations. I like to think that his decision was rooted in a deeply held belief about the shared preciousness of life. “We are caught in an inescapable network of mutuality, tied in a single garment of destiny. Whatever affects one directly, affects all indirectly,” wrote the Reverend Dr. Martin Luther King, Jr.

Regardless of his reasons, our connection as donor and recipient is extraordinary. Having received his stem cells, which found their new home in my bone marrow, I share his immune system and blood type. My birth-given immunity is no more. Right down to the cellular level, I am forever a brother to an individual to whom I am not related and do not know. How remarkable is this!

It is all too easy to take each other for granted. We look and pass each other on the subway and on the street, at work and at school, without a second thought. Lost in ourselves, too often we forget how each of our lives is so intimately interwoven. As the recipient of an unrelated donor transplant, I am keenly aware that these so-called strangers are far more familiar than the word suggests.

Somewhere out there is a brave individual who saved my life and inspired hope. In a world often depicted as mired in chaos and hate, stories such as this touch our tender, aching hearts and renew our faith in what is possible. While I continue to keep an eye out each morning for my hero, I encourage you to also be open and on the lookout for the innumerable ways in which your own life and that of others are bound together. One never knows in what positive way a stranger may shape another's life.

Ask the Survivor: Careers after Cancer

Q *What prompted you to make a career change after your cancer treatment? How did you begin the process and follow through?*

A When I got my cancer diagnosis, I was working at a job that paid the bills but it wasn't my dream job by any stretch of the imagination. I had thought about changing career paths for several years, but I just had not been adequately motivated to take the steps necessary to make that change. For me, as for many people I know, the experience of my cancer diagnoses and related treatments opened my eyes in some ways to recognize the things that are important to me in my life. It also gave me a lot of free time to browse the Internet looking at different career and educational options. For me, my own experiences with cancer and other chronic illness led me to think that a career in counseling might be a better professional fit for both my passion and my skill set than the job I was in at the time.



By Brian Wickman

Brian is currently pursuing a master's degree in social work and a master's in divinity at Columbia University. He also sits on the Board of Directors of First Descents, an adventure therapy program for young adult (18-40) cancer patients and survivors.

It's one thing to have an idea about effecting change in one's career, but it is quite something else to actually find a way to do it. The challenges for me have not been insignificant. I am currently

starting my fourth (and hopefully final) year of a master's program at Columbia. I chose the program not only for its academic suitability, but also based on the type of insurance offered to students. As an amputee who sees nearly a dozen specialists on a regular basis, I cannot afford to choose any school program or job without a rigorous review of their insurance offerings. I also underestimated the side effects of my treatments. My memory does not function as it once did, and physically I get fatigued more often and more quickly than I did precancer. I have also found that most people just don't understand how a disease that I was treated for five years ago could still be impacting my life today.

I've learned to become my own best self-advocate. I have learned to seek out people who will listen to my needs and help me achieve my goals. I listen to my body very carefully and try to give it what it needs. I don't know what the future holds for me professionally or in terms of my health...but I am slowly working toward creating opportunities to become more fully the person I am meant to be.

Resource Review: **BE** **THE MATCH**[®]

Be The Match Registry is the new name for the National Marrow Donor Program[®] (NMDP) Registry. Be The Match offers people the unique opportunity to help a patient by donating bone marrow or umbilical cord blood. Thousands of patients with leukemia, lymphoma, and other life-threatening diseases depend on the Be The Match Registry to find a match. A patient's doctor can contact the NMDP to search the Be The Match Registry and other registries worldwide to access nearly 16.5 million donors and nearly 550,000 cord blood units.

Do all donations involve surgery?

The majority of donations do NOT involve surgery. Today, the patient's doctor most often requests a peripheral blood stem cell (PBSC) donation, which is nonsurgical. The second way of

donating is marrow donation, which is a surgical procedure. In each case, 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 to save a patient's life. The donor's immune system stays strong and the cells replace themselves within four to six weeks.

Is there a cost associated with donating?

Donors never pay to donate. We reimburse travel costs and may reimburse other costs on a case-by-case basis.

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

9/11 New Life: Endless Possibilities



By Donna McClure

Donna McClure has worked in healthcare for more 30 years as an administrator and consultant, and most recently, in healthcare sales. Over two and half years ago, she was diagnosed at MSKCC with ovarian cancer and has overcome two surgeries and ongoing chemo treatment and continues to fight the good fight. This story is a true reflection of her experience on 9/11 and her gratitude for being alive to witness the birth of her two grandchildren.

Almost ten years ago, a business associate and I rescued his wife from the streets of lower Manhattan on 9/11. We made it through numerous police barricades to find her during the chaos in a building on Wall Street. Many poignant memories of dust-covered Wall Street executives and the absolute silence in lower Manhattan have stayed with me.

Since then, I have searched carefully to find good, looked for ways to make the most of each day, and never allowed the evil I witnessed that day to permeate my soul.

On another date with 9 and 11 in it, I witnessed the birth of my first two grandchildren both born on March 9, 2011, in different states! My granddaughter Grace was born in Nyack, NY, and I was able to see her within minutes of her birth. I cried tears of joy for the promise of new beginnings in the eyes and soul of this beautiful being I was blessed to hold. Five minutes later, my other son called to say that his wife's water broke and they were on their way to Dartmouth Medical Center in New Hampshire. There are no words to describe the joy and anxiety I felt at the realization that two grandchildren were most likely going to be born on the same day.

I took a nap at 3:00 AM and went back to have another quick peek at my angel Grace around 10:00 AM before I headed north to New Hampshire. No calls while I traveled north for four hours resulted in super Grammy becoming anxious Grammy. Miles joined us at 11:23 PM, a few minutes before the end of March 9, 2011! The gratitude I felt to witness this sacred event again is a treasure I will cherish forever.

For the past two years I have personally struggled with the fight of my life. I survived two surgeries and continue to endure chemo and clinical trial drugs. For now I am winning the latest round against stage III ovarian cancer. I pray that someday my grandbabies and I will dig in the dirt, look at birds, swim in the ocean, read books, laugh out loud, walk in the sun, and share the wonder of living in the moment every day. I share gratitude for the opportunity to be alive and acknowledge the wonderful day that gave me new life and two powerful reasons to fight the good fight.

So for me the numbers 9 and 11 mark a hope for tomorrow every time I look into the eyes of these beautiful, healthy babies. I pray that the world they grow up in will be filled with optimism and a belief that good will prevail over evil and a sense of wonder that life has endless possibilities.

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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 contact Marina Lenderman at 212-639-5329 or e-mail patient2patient@mskcc.org.

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Bridges is a publication of the Memorial Sloan-Kettering Cancer Center Survivorship Initiative.
Produced by Medical Graphics and Photography.