



Hope and Glory

By Peggy Patteson

Peggy Patteson and her husband own the Hope and Glory Inn in Irvington, Virginia. Prior to her cancer diagnosis, the inn was her life. She is grateful that something as terrible as cancer made her focus on the important things in life – her children and grandchildren, friends and the incomparable joy of just being alive.

The day cancer came knocking at my door was the most frightening day of my life. It later turned out to also be one of the most important days of my life. My journey back to life took many turns.

My story began with a lump on my neck and a visit to my doctor who suggested that it was merely

menopausal. Though she was reassuring, I decided to get a second opinion from an ear, nose, and throat specialist.

I cannot describe how devastating it was to hear that this doctor believed that lump was stage IV cancer; he wanted to operate immediately. In haste to prove him wrong, a trio

of physicians was called in. They concluded that it was a brachial cleft cyst and that I need not worry. My hopes were restored.

Surgery was scheduled a few weeks later. In yet another reversal, I was told that the lumps were indeed metastasized cancer from my tonsils, which were removed during the surgery. The shock of hearing – again – that I had stage IV cancer was overwhelming.

Now my husband sprang into action and asked for help from a respected oncologist he knew. It was his call to Dr. P at Memorial Sloan-Kettering that began my journey back to life.

We got an appointment within days. We met with Dr. P, who was kind and gentle, but very straightforward. He said I had a difficult road ahead: feeding tubes, nausea, fatigue, all were normal symptoms, and I would likely suffer for several months. Still, his confidence erased the lack of faith I had developed in the medical community.

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Memorial Sloan-Kettering
Cancer Center



This past December 23, 2011, marked the 40th anniversary of the National Cancer Act of 1971 signed into law by then-President Richard Nixon.

Although the Act did not mention the word "war," many referred to the law as "The War on Cancer." For me, it is a striking thought to be a cancer survivor for 33 of those 40 years.

The National Cancer Act of 1971 put the focus on cancer research. Success has been achieved through improved early-detection techniques, treatment discoveries and standards, and clinical

trials. Oncologists are discovering less-toxic methods of treatment and targeted therapies, and significant progress has been a result of cancer research in the biology of cancer, risk factors, and prevention. The number of cancer survivors in 1971 was three million and in 2008 it was estimated to be 12 million. The author Siddhartha Mukherjee, who recently wrote the biography of cancer, called *The Emperor of All Maladies*, focuses his book on the history of cancer, referring to both patients and clinicians as "soldiers" in battle, just like a war. However, the War on Cancer has not been won yet. Cancer still accounts for more deaths than heart disease and still claims 1,500 people a day.

Bridges has now published 15 issues, with close to 75 cancer survivors sharing their stories.

We would like to hear from more cancer survivors about their journey. If you need help putting your thoughts on paper, please let us know. We have editors who can assist you via e-mail or in person. Just e-mail us at bridges@mskcc.org with any questions.

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He directed me to a radiation oncologist, Dr. L. She said, "Mrs. Patteson, you have cancer, a bad thing. But you happen to have a good cancer and I am going to cure you. I can say that because I have had 116 tonsil patients and I have cured 113 of them. Two of the three really were not mine." No more wonderful words could have been spoken. Cure was a word I had not heard until that moment.

July 4, 2006, I moved to Manhattan and started a journey that has changed my life. From the moment I walked through the doors at MSKCC, I felt

safe. My doctors were brilliant and they treated each patient like family.

Although it sounds strange, my journey turned out to be one of the best years of my life because of the lessons I learned. I had never enjoyed being out of my comfort zone. I was now in the biggest discomfort zone of my life. But I believe things happen for a reason.

I realized that working in hospitality for over 26 years required me to always put others first. For the first time in my life I had to think only of me. Amazingly, what I discovered was how many people love and care about

me. I would have never known this had I not gone through this battle with cancer.

I faced the biggest challenge of my life, and I knew that if I could get through this I could do anything. But I could not have done it without the help, guidance, support, and love of my husband, children, family, friends, and the brilliant staff at MSKCC.

I want to share what my five-year-old grandson, Hunter, told me when he came to visit me after my first round of chemo: "Mimi, failure is not an option. Believe in the Hope and then there will be the Glory!"

One-line coping strategies:

- Keep calm and carry on
- Laugh A LOT
- Be creative and find ways to feel useful



A Family Affair

By Kate Niehaus

Kate Niehaus is originally from Corning, New York, but has lived in the New York metro area (Rye and now Manhattan) with her husband, Bob, for all of her adult life. She had a career as a full-time mom to their three children until several years ago when her youngest child started college. Since then she has been actively involved as a patient advisor at MSKCC, serving as a Patient-to-Patient volunteer and as a member of the hospital Ethics and Quality Assessment Committees.



I have had breast cancer twice and melanoma once, but at least on paper, the biggest cancer risk that I now face is actually colorectal cancer. This may be the most important piece of information I got as a result of coming to Memorial Sloan-Kettering for a consultation after my first breast cancer diagnosis. I am a cancer survivor, but just as important, MSKCC's Clinical Genetics Service is helping my whole family to survive.

Eighteen years ago, after being diagnosed with DCIS (very early stage breast cancer) I filled out a survey that was given to me by Clinical Genetics. As a result of information I provided about my family medical history it became clear to the doctors on the service that the prevalence of colon and uterine cancer was highly suggestive of Lynch syndrome (later confirmed with genetic testing, which was not available at the time). This rare syndrome is associated with an 80 percent lifetime risk of colorectal cancer, 60 percent lifetime risk of endometrial cancer, and higher than average risk of ovarian, urinary tract, small intestine, stomach, biliary tract, and brain cancer. It was on the advice of Clinical Genetics that my three sisters and I began an intense screening program including annual colonoscopies to watch for early-stage changes.

Eight years later, my younger sister, at age 39, was found to have early-stage colorectal cancer during one of her screening colonoscopies. Given that current screening recommendations for the general population suggest

colonoscopies be done starting at age 50, I feel certain that my sister's cancer would only have been detected at an advanced stage without the intervention of MSKCC. On the advice of her doctors, my sister chose to have a subtotal colectomy and is now healthy, living in Los Angeles with her husband and two children and teaching law.

At almost the same time that my sister was diagnosed, a genetic test became available in research and commercial labs so that my other two sisters and I could confirm our Lynch status. Since that time we have all chosen to have prophylactic hysterectomies/oophorectomies and continue our endoscopic screenings. We now know that while our risk of developing colorectal cancer is high, with vigilance and adherence to screening recommendations we should remain healthy.

Ironically, the common link we have through this difficult genetic finding has brought my family closer. We share the fear of the disease and the grind of screening, and we help one another along by doing bowel prep coaching, nagging one another to schedule our procedures, and following up on pathology reports. And, as we are spread out across the country, we share information that we have gotten from our doctors in order to ensure that we are following the latest protocols and recommendations. We are all in this together.

Recently, our focus has shifted to the next generation. As our children have grown we have found that we are increasingly concerned about their

genetic predispositions, and as each has reached adulthood, we have encouraged genetic counseling and possible genetic testing. To date, of the 11 children in this group, seven have already tested and three of them carry the mutation. Those three have all started screening, and clearly the payoff has already begun, as one was found to have a polyp, a necessary precursor to cancer, at age 22. These fantastic young adults will have to be vigilant about Lynch syndrome for the remainder of their lives, but we know that with rigorous screening and scientific developments that are likely ahead this clan will remain strong in spirit and in numbers.

Some people would view my family as having "bad luck," but my attitude is that we are incredibly fortunate to have stumbled upon the brilliant minds in MSKCC's Clinical Genetics Service during my breast cancer treatment. I have learned that people inherit risks for many diseases including diabetes, Alzheimer's disease, and cancer, but only some of us are able to test for and act on these risks. I also credit my father, George Southworth, who, although enduring treatment for prostate and colorectal cancer over many years, had the foresight to contribute a tumor sample before his death so that his children could benefit. I wish he were alive now to see what strides have been made. He would be fascinated, pleased, and relieved since genetic testing, paired with vigilance, should ensure that his progeny will live longer, healthier lives.



Many genetic testing laboratories have begun a practice of direct-to-consumer marketing of their tests through print and television advertisements. Direct-to-consumer (DTC) marketing refers to the targeting of advertising to the end consumer, which in this case would be the genetic test recipient, rather than to the ordering healthcare provider. We interviewed Emily Glogowski, a genetic counselor at MSKCC, about the implications of this for cancer survivors and their families.

Q How can genetic counseling be helpful?

A Receiving genetic counseling from a trained professional has many benefits because ordering and interpreting appropriate genetic testing is more complex than many realize. For example, few realize that genetic testing for cancer is not useful for everyone because most cancers are not hereditary. The selection of tests should be individualized, based on personal and family history. Genetic counselors can help patients navigate decisions regarding which tests should be given and in which order. Also, test results can be ambiguous. Interpretation by a genetic counselor offers personalized risk-management recommendations and referrals for the patient and family members.

Q How may DTC marketing affect current medical practice?

A DTC ads compel viewers to request these tests from their doctors, often without any genetic counseling. Anticipated

benefits of this approach include greater public awareness and access to testing for those who are unable or unwilling to attend a specialized clinic. However, the strong messages portrayed can heighten fears about cancer, generating demands for expensive tests that may not be medically necessary. Many physicians are untrained or too busy to handle these delicate conversations.

Q What changes have you noticed in the genetics clinic?

A We receive a disproportionately high volume of patient requests for genetic tests that receive media attention (such as *BRCA1/2*). One consequence is that insurance companies have become the gatekeepers. It is now more difficult to obtain reimbursement for genetic testing, even for those who truly need it. Another is recipients' lack of emotional preparedness before testing. People have come to us in tears, with misunderstandings and regrets. We wonder how many others have been tested without adequate counseling and feel unnecessarily frightened or falsely reassured.

Q How has advancing technology complicated issues surrounding genetic testing?

A Modern technologies allow sequencing through a person's entire set of genes, instead of a selected one or two. These "genomic tests" do hold promise for personalized medicine. But, as with any new technology, this one brings potential for harm. Start-up companies are marketing and, in some cases, providing these tests directly to consumers. Regulatory oversight is limited. Scientists' ability to interpret genomic findings is in its infancy, and the psychological and social implications of this testing are unclear.

As such, the time for dialogue among scientists, healthcare providers, policy makers, and consumers is now. Together we can develop a strategy to target this bold new technology to the areas where it can do the most good, with optimal safety and effectiveness.

To inquire about whether genetic counseling is appropriate for you, call 646-888-4050 or visit www.mskcc.org/clinicalgenetics.

Ask the Survivor: Advocating for Your Health

By P. E. Gibson



Q *As an older cancer survivor, how have you advocated for your health? Have the Internet and social media been helpful?*

A I'm a dual cancer survivor, meaning I'm someone who's been diagnosed twice with cancer, once with renal cell carcinoma of the left kidney (organ confined) in December 1996 at age 65, and once with prostatic adenocarcinoma in June 2004 at age 73. Not knowing what to expect health-wise after my treatment was over stressed and worried me constantly.

Admittedly, worrying about my post-treatment health has never gone away. You never forget the fact that your cancers could come back. As a survivor I found that talking openly to my doctors was essential, as we both needed to share information in order to manage post-

treatment plans and overcome future problems. Also, the follow-up care and treatment guidelines I received forced me to think about locating helpful support services. And the support services I discovered over the Internet were precisely the help I needed. I felt the loss from less attention and support from my previous healthcare providers, and I needed the continuing post-treatment support attention from these newly developed resources.

Consequently, using the Internet I set out to find healthcare literature resources to help me understand the important aspects of all of my diagnosed chronic diseases. These resources included *Life After Cancer Treatment* (1996 and 2004), *Living with Hypertension* (1996), *Living with Chronic Kidney Disease/Nephrectomy* (1996), and finally *Living with Chronic Lung Disease* (2008). I found myself to be a "positive deviate" in learning how to maintain and focus on positive care practices to monitor and help me survive

these critical illnesses. Health reference books helped me recognize what constitutes reliable medical content, and these resource materials most certainly helped me to balance and restrict all of my fears positively. The glass is always half full.

Common values and knowing what's most important to you can help conquer personal fears in life, even in health. Patient-empowerment practices have provided me with extraordinary support in dealing with my complex health crises. For example, I found a wealth of informative websites for patient self-advocacy on the Internet. Ultimately, I've helped myself survive by doing one vital thing: recognizing the existence of healthcare disparities and that certain chronic illnesses lend themselves to early detection, preventive medicine, and evidence-based medical practices. Post-treatment guidelines, federal agencies, nonprofit organizations, and all of your current medical practitioners should never be overlooked as potential resources in optimizing your health. *Fortunately, I now find all cancer survivors my best personal friends and associates.*

What's ahead? This year I've been pleasantly surprised by social media's involvement in strategic healthcare pursuits. While I'm not literate in social media, I've learned a little about social media such as Facebook. Recently I watched a live webinar from the HealthWorks Collective called *The Socialization of*

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Resource Review: MSKCC's Integrative Medicine Herbs and Botanicals Website

MSKCC's Integrative Medicine Service staff, led by a pharmacist and botanicals expert, has developed a comprehensive Web resource that provides evidence-based information about herbs, botanicals, supplements, and more. Herbs and botanicals are often taken for cancer prevention, symptom control, treatment, and general health purposes. Though many of these products are branded as

being natural, this does not always equate to safety and effectiveness.

To help individuals better understand the often confusing claims made for over-the-counter products and regimens, the site offers more than 250 detailed monographs, with each providing a clinical summary of the agent and details about constituents, adverse effects, interactions,

and potential benefits or problems for cancer patients. It is important to ask your doctor or another qualified professional about possible interactions with your specific medications before taking any supplements. MSKCC's Herbs and Botanicals website is continually updated as new information becomes available. It can be accessed by visiting www.mskcc.org/aboutherbs.

How Lucky Can One Man Get?

By Tom Chiu

Tom Chiusano born June 29, 1947, to Carmine Vito Chiusano and Ethel Sandin Chiusano in Jamaica, Queens, New York. He graduated from Pelham Memorial High in 1965 and St. Bernard College in 1970 (shocking many, including himself). He married Penelope Watson on June 18, 1976. His family also includes his son, Tim, daughter-in-law, Kelly, and two grand potbellied pigs. He is not a Grateful Dead fan but “what a long strange trip it’s been,” and he hopes to keep on truckin’!

I am a very, very lucky man. I have a loving wife, son, and daughter-in-law. I come from a big Italian/Irish family (number four of eight) with all the good that implies, especially at holidays. In 1991 I had a mole removed from my back by my dermatologist. It turned out to be early-stage melanoma. A skilled surgeon took over, making sure all the tissue in the area was clean. Seven years later I developed two tumors, one in my left collarbone and one in my right underarm. Both were excised using a procedure that included removing the lymph nodes under my right arm. Thirty days later, my wife noticed a small red bump in my right underarm. I went back to see my surgeon who said, “It’s back and it’s inoperable.”

My little red bump went from the size of a grape to a grapefruit in what seemed like the blink of an eye. Now under the care of an oncologist, I went from being

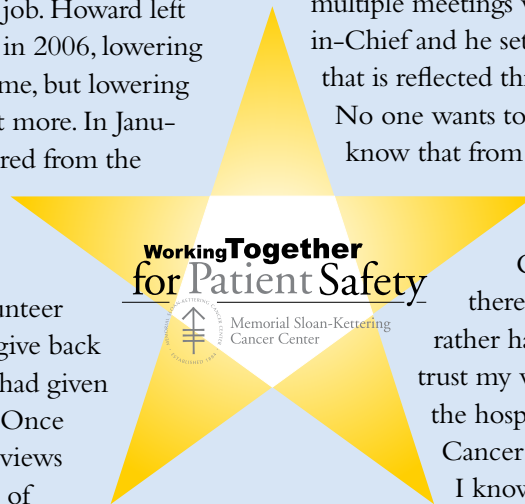
a candidate for a preventive serum to a stage IV patient with a prescription for a new protocol named CVD-bio in that same blink. CVD-bio is a combination of five chemo drugs administered on an inpatient basis for five consecutive days, four cycles, over a 12-week period; that was great in retrospect but horrible while it was being administered. For you horror movie fans, I could have been Linda Blair’s stunt double in *The Exorcist*. The side effects were severe. I could vomit or levitate (something called the rigors happened frequently and had me almost shaking myself out of bed) with the best of them. I lost 40 pounds, my hair fell out. I went from being a fairly normal-looking 50-year-old male to a yellow, skinny shell who needed suspenders to keep suit pants up. Somehow, with the help of my wife, my son, my nurses, and doctors, I made it. Here’s why I am among the luckiest men alive: Of the 80-plus stage IV melanoma patients given CVD-bio, I am the only one who survived. Why me? All I can do is point to the list I just gave you.

At the time, I was the General Manager of 92.3FM, known then as K-ROCK, better known as the home of Howard Stern. It was a great job, high profile, high stress, but a great job. Howard left for satellite radio in 2006, lowering the stress level some, but lowering the fun level a lot more. In January of 2008 I retired from the radio business; I was ready for something else. I was ready to volunteer at MSKCC and give back to the place that had given me back my life. Once I passed my interviews with the director of

Volunteer Services and the Patient Safety Director, I started on the Patient Safety Committee. I am now the Volunteer Co-Chair of the Patient Safety Rounds Committee, which is in charge of having patient volunteers survey current patients to learn about their experience to see if anything can be done to improve their care. I am also a Patient-to-Patient volunteer, someone who talks to patients needing to speak to a kindred spirit. I have spoken at the “Relationship-Based Care” seminars given to the nurses and participated in StoryCorps, a joint effort between the hospital and National Public Radio. I was also a member of the “OR Sharps Injuries Reduction Team.” The team successfully promoted sharps safety practices in the OR (passing sharps back in forth through a neutral zone, for example, and using blunt suture needles). The team also improved the process for treating staff injuries from sharps. Whatever I have given the hospital has been returned to me tenfold in my sense of self-worth.

I can’t say enough about my doctors and their teams. I don’t care if I’m redundant when I praise the nurses at MSKCC — they are the heart and soul of the best cancer care in the World. I’ve been in multiple meetings with the Physician-in-Chief and he sets the tone of caring that is reflected throughout the hospital.

No one wants to be a cancer patient. I know that from my own experience as well as my wife’s two scares with “the C word.” However, there is no place I would rather have been treated or trust my wife to. I believe in the hospital’s slogan “the Best Cancer Care Anywhere.” I know it’s true.



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Breast Cancer (October 25, 2011). On the occasion of Breast Cancer Awareness Month, the webinar cited the growing role of social media in educating breast

cancer patients and connecting them with the treatment resources they need. In addition, I read an article in the *Wall Street Journal* called “When Patients Band Together, Doctors Listen” (August 30, 2011), which discusses examples of how

patients have used social networks to spur research for rare diseases. Articles like these illustrate the potential importance of collaborative healthcare efforts in the future.

Surviving Survivorship

By Cindy Graeff

In August of 2011, I went on a two-week journey. It wasn't a vacation, but it was just as rewarding. My journey was from Dallas to Manhattan. My journey was to finally obtain answers to the question, What's been stealing from my quality of life? In the early '80s I received mantle radiation for Hodgkin lymphoma, followed by radiation in 2006 for breast cancer and chemo for both breast cancer and Hodgkin lymphoma. The radiation side effects I endure are: cardiomyopathy; substantial muscle atrophy in the neck/shoulder/arm/hand/fingers; and loss of motor skills, strength, sensory function, and coordination. The associated pain, tingling, stinging, numbness, and weakness are nonstop. They keep me from sleep, work, everyday functions we all take for granted — pulling up pants, brushing teeth, preparing meals, cracking open a beer bottle (or water), showering, clipping nails, washing dishes (preferably not cutting off a finger in the process), buttering bread. Reaching into a chip bag and coming out with nothing is extremely frustrating! Hobbies I've had to leave behind include guitar playing, landscaping, walking, and making art.

It took me years of searching to find answers. Why am I having these symptoms? Why are they getting progressively worse? Why is it the more I use my hand/arm, the more I lose it? Why don't I get better? My oncologist, radiologist, and primary care doctors didn't know. Finally, an orthopaedic surgeon diagnosed me with radiation-induced brachial plexopathy (RIBP), but offered no treatment to repair it. That sent me on an Internet search — what is this RIBP? I eventually landed on an article written by an MSKCC physician written in June 2011. The article discussed quality-of-life issues relating



Cindy Graeff is the youngest of four, born in the 1950s and raised in Reading, Pennsylvania. Dallas, Texas, has been her home since 2001. She is a life partner, a daughter, a sister, a niece; she is “Mommy Cindy,” an aunt, a cousin, an avid dog/cat lover, a loyal friend, a confidant, an advocate of many causes. She is always the skeptic in the room, and although she is nowhere near being a “princess,” those closest to her say she is a “royal” pain.

to the nerve damage caused by radiation. I e-mailed the author my story and he suggested I come to MSKCC's Rehabilitation Center for evaluation, diagnostic testing, and PT/OT sessions. It was challenging and expensive to cram this into a two-week period, but I needed to take the chance that they could provide help.

Tests confirmed the RIBP diagnosis — severe radiation damage to the bottom and midsection of the brachial plexus. This damage will not heal and there is no magic pill that will help. It is the casualty of the war against two cancers that won my survival. It was a relief to have a physician and medical facility acknowledge the brutal cancer treatments I had endured and affirm their impact on my quality of life. This helped me understand, gain strength, and accept my survivorship. Knowing what, why, and how this had happened to my body brought me closure, which is priceless.

On my last day at MSKCC, I hugged the doctor and the PT/OT staff, crying happy tears.

Dr. S shares his RIBP knowledge and skills within the medical profession. With knowledge and information is born the need for research for kinder treatments that enhance survivors' quality of life while killing the darkness of cancer. As survivors live longer, there is a need for more Dr. S's in the world.

Now, I continue at home in Texas with the PT/OT plan established at MSKCC's Rehabilitation Center. Though I still have pain, I also have answers, an understanding and hope for more medical research and physicians to aid those just trying to survive survivorship.

Cheers and continued success to Dr. S and MSKCC.

Stay Strong.

Signs and Such

By Amy Dempsey

Born in New York City, Amy has lived most of her life in Bergen County, New Jersey. There she married her high school sweetheart and raised three wonderful children. Since her breast cancer diagnosis Amy has found journaling to be both satisfying and helpful in maintaining a positive outlook on life's challenges.



I like signs. They can leave you with a strange feeling or a powerful message. Sometimes the signs I come across in my daily life make me wonder if it was more than cancer that brought me to where I am today.

A couple of months before my breast cancer diagnosis, I was laid off from work. This allowed me the luxury to care for myself and be more available to my brother, Garry, who recently had been stricken with ALS. What was the chance of all three crises happening nearly at once?

Trying to decide between a hospital in New York and one in New Jersey, I began noticing many New York license plates bearing the letters M-S-K or A-M-Y. I got the message loud and clear.

My insurance company became networked with MSKCC just at this time, giving me a choice and making my decision more clear.

The chemo nurse and the nutritionist at my first treatment had the same names as my two daughters, Anne and Cara. Immediately I felt reassured. When I think of all the names there are in the world, *this* had to be more than coincidence.

An opening at a very highly regarded nursing home became available just as my brother desperately needed to be placed in one. The waiting list and his circumstances had made the chances of this working out in his favor almost nil.

A brand-new social worker at the nursing home turned out already to have known my brother for more than ten years. Having someone familiar with Garry was a great comfort, especially as he had lost the ability to communicate. I was convinced that there had been a Divine Intervention.

The day my brother passed away I was in the car when a hearse appeared alongside. What drew my attention was how the vehicle rode right next to me for an exceptionally long time. I finally realized the name on the door was that of the funeral parlor where my father had gone 28 years before. It brought me solace as I felt Dad's presence.

I would be thinking about Garry and, checking the expiration date stamped on a milk carton or a bag of chips, see his birthday. (This I admit often occurs with other people on my mind as well.)

I had been busily writing in my journal and also feeling that I would like to share it with others. Afterwards I went to the Stop & Shop. As I was paying, the cashier swiped my store card and, reading my name on her screen, remarked, "What a great writer's name you have." Was writing my new destiny?

The day I ended my memoir, I told my sister I wanted someone who could be objective to read it. Hours later she e-mailed an article from the Internet about the MSKCC Visible Ink program. Wow, another good omen!

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

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.



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

