Bridges

CONNECTING CANCER SURVIVORS

VOL. 8, SPRING 2010

My Dirty Secret

By Jenny Isaacs

Jenny Isaacs is a clinical psychologist who works as an assistant professor in psychology at Yeshiva University and volunteers as a breast cancer advocate and supports breast cancer wellness services through education, advocacy, and research.

I was 31 years old, it was Valentine's Day, and I was alone. Watching a world filled with couples, chocolates, and cutout cupids, I couldn't imagine feeling sorrier for myself. Then the doctor told me I had breast cancer.

Throughout the double mastectomy, chemotherapy, and breast reconstruction I worked two jobs — one that paid the rent and the other as a cancer patient. I lived in both the world of the well and the world of the sick. It is hard to capture in words the tremendous pain, fear, anger, and overwhelming sense of loss that came to me when I was diagnosed with cancer. I was sure that nothing good could come out of something that seemed so horrible. Although there was no specific day that I became a "survivor," slowly over time I was evolving into one. I joined a support group, became a patient advocate, started a new form of treatment (i.e., acupuncture), and began volunteering for a cancer wellness center. I returned to my regular workouts, and began to eat healthier and remove some of the physical and emotional toxins from my life. I was a warrior of wellness, making small strides every day. My dirty secret was that I was still a smoker.

I had smoked on and off since the age of 15. I had quit more times than I care to remember. I quit and restarted two times after my diagnosis. But once I was finally becoming healthy again I knew I needed it to stick, so I took a very different approach. The first crucial piece to my success had been set in motion months ago. I had begun to develop a new identity. No longer was I the immortal party girl; instead I was a woman trying to immerse herself in wellness. I was ashamed of being a secret smoker. The rest of my life seemed out of sync with my life as a smoker.

The second step for me was to get help and to lay it on thick. The pride that kept me fighting this battle alone kept me smoking. I enlisted a treatment team and employed as many smoking-cessation aides as possible. I went on an antismoking medication, began seeing a brilliant cancer and smoking-cessation expert at MSKCC to guide me through the process, eventually started using the nicotine inhaler, incorporated more cardiovascular exercise into my routine so I could feel the changes that would occur as my smoke-free body began to repair itself, met with a therapist to support me with this and other issues,

Continued on page 7

In this issue

If you are interested in
submitting your story,
please visit
www.mskcc.org/bridges

Memorial Sloan-Kettering
Cancer Center

Editorial *by Eileen Gould*

Spring 2010 is our eighth issue and it completes the second full year of publication of the MSKCC newsletter *Bridges: Connecting Cancer Survivors*. *Bridges* was awarded a 2009 Communicator Award, which honors Creative Excellence as judged by the International Academy of the Visual Arts.

There have been many wonderful stories of hope and survival written by our cancer patients. Also there have been informative articles about state-of-the-art treatment and aftercare for cancer survivors submitted by our clinicians in the "Ask the Professional" column.

We have tried to cover a wide variety of topics relating to survivorship as well as specific age groups of patients. We hope that our readers have found this a worthwhile and informative forum for both patients and their families to express themselves and share their experiences with one another.

As we embark upon our third year of publication, we continue to be receptive to input from our readers and encourage you to send us suggestions and recommendations for future content of the newsletter. Furthermore, we are currently accepting story submissions from MSKCC patients and family members that are approximately 500 words in length. You can contact *Bridges* via e-mail at bridges@mskcc.org, on the Web at www.mskcc.org/bridges, or by regular mail sent to MSKCC Bridges, c/o Meghan Newcomer, 1275 York Avenue, Room M2001-K, New York, NY 10065.

It is a privilege to be the Patient Editor of *Bridges*, and I look forward to many more stimulating and informative issues.

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

Ask the Survivor: Managing Anxiety

By Rachel Rusch

Rachel Rusch is a 25-year-old survivor of neuroblastoma. Originally from Texas, she now resides in Brooklyn and makes her living in the arts.

As my annual oncology follow-up appointment approaches, I find myself getting very worried. Do you have any suggestions for managing this anxiety?

Absolutely. Let's start with acknowledging that you are not alone in feeling this anxiety. As survivors of cancer, we hold the delicate nature of health in a very precious place. Allowing yourself to voice worry can be the beginning to finding the outlets that best work for you.

If the time since your last follow-up appointment has been healthy and with little complication, perhaps a celebration is in order. Take yourself out to dinner, journal about the things you have discovered over the past months, plan a family outing. Perhaps a joyous ritual can be established, creating a mindset that your appointment is a celebration of your life.

Anxiety surrounding annual follow-up appointments can be increased if the year has been more trying. After a difficult year of health, there can be a greater deal of anxiety leading up to an appointment. There can be fear of what might be found, or of having to go back to a hospital. Remember, you are not alone. If we keep fears and anxieties to ourselves, we are ignoring the greatest gift I know survivorship has given me — a hunger and want for life, health, and connection.

The support found in loved ones and doctors can be astounding. Writing creatively, journaling, going for long walks in the park, listening to music, or calling up a friend for a cup of tea are all incredibly useful outlets. In these moments, we can come up from under our anxieties and look forward to appointments as a time to continue to persevere in our health and maintain the best life possible.

Ask the Professional: Managing Stress

By Barbara Golby, LCSW

Barbara J. Golby, LCSW, is a clinical social worker in Memorial Sloan Kettering's Post-Treatment Resource Program. She has been helping individuals and families cope with the emotional and practical challenges of cancer and other serious illnesses for 12 years.

Q What are the factors that contribute to post-treatment-related stress?

A Receiving a diagnosis of cancer can add considerable stress to our already busy lives. One common misconception among survivors is that the end of treatment will bring relief from stress and a return to life as usual. But while there may be some relief that treatment is over, many people find that they now have a whole new set of concerns and unfamiliar feelings that they did not anticipate.

Feelings of sadness, anxiety, vulnerability, a sense of aloneness, and even abandonment are not uncommon for new survivors. This can be disconcerting and difficult to understand. But consider the following: Perhaps for the first time since diagnosis, you, your family, and your medical team are no longer single-mindedly focused on fighting your cancer. After spending so much emotional and physical energy on the one goal of getting better, it can be hard to know how to refocus your attention, especially with lingering fears of recurrence. To make things more challenging, the reassuring doctor's visits no longer occur as frequently; family and friends eagerly anticipate the return of your old self; and life's other responsibilities, the ones you may have set aside when you were first diagnosed, are tugging at your sleeve, vying for their share of your attention. Add to that the likelihood that your treatment has left behind reminders of your cancer in the form of physical changes that require their own adjustment. Is it any wonder that the transition to post-treatment can be so stressful?

Q What are some helpful ways of managing stress during the post-treatment period?

A • First of all, remember that having a difficult time getting back into life after treatment is perfectly normal. There is nothing wrong if you don't feel like celebrating the end of treatment. You have just been through a life-changing experience and transitioning to the post-treatment stage is a gradual process.

- Enlist the support of family and friends. Educate them by explaining that although you may have completed treatment and are hopeful about the future (if this is indeed how you feel), it takes time to adjust to the physical and psychological changes that follow diagnosis and treatment. Reassure them that you are eager to be back on your feet and that you welcome their patience and understanding.

- Become aware of how your body responds to stress. Do you become nervous anticipating a trip to the clinic for follow-up scans? Does the thought of returning to work leave you feeling overwhelmed? Do you find that you eat more, sleep less (or the reverse), or become irritable, impatient, or withdrawn? Becoming familiar with your body's reactions is the first step in learning new ways of responding to stressful situations.

- Get involved. If you are not ready or are unable to go back to work, then volunteer with an organization you care about or enroll in a class you've always wanted to take. Having a routine and something meaningful to focus on can help you to reengage at your own pace.

- Find an outlet for self-expression — whether it's a support group to help you feel you're not the only one, counseling to help you understand your feelings, or painting, poetry, or dance. The possibilities are endless.

- Invest time and effort in taking care of yourself. Eat a balanced diet, see that you get enough exercise and sleep, and seek out activities that bring you pleasure and help you to relax. These things may not decrease the level of stress in your life, but they will leave you with a greater sense of well-being and strength to manage your stress more easily.

Story of a Four-Year Ovarian Cancer Survivor

By Diana Endara DeMeo

My story is one of exceptional doctors, family, and friends, all of whom I call *Angels*.

It was a chain of events, each event unfolding to teach a lesson that I trust can help others.

The only reason I attended my yearly appointment was a letter from my gynecologist announcing her retirement. A mild pain during the examination, my age (50s), and family history (my brother's cancer) prompted her to recommend a sonogram. She was *my first Angel*.
Lesson: A yearly check-up is important, even if you feel fine.

When making the sonogram appointment, I was told there was nothing available for four months. I immediately called my doctor's office. Her assistant, *my second Angel*, said, "Let me call them. If there's something there, do you know how much that can grow in four months?"
Lesson: Don't take no for an answer.

The radiologist found a suspicious nodule and recommended follow-up in six months. However, when my new gynecologist got the results, although my CA 125 was normal, she said, "Sure, I'm going to follow up, but I want that thing out now!" She was an *Angel* who was key to my survival.
Lesson: Trust your doctor's recommendations even if they're not what you'd rather hear.

During surgery, the lab confirmed cancer. Chemotherapy, my biggest fear, was the next step.
Lesson: Deciding on less frightening treatments is a big mistake.

When given the option of choosing the hospital for treatment, the choice was obvious, MSKCC. My oncologist was another *crucial Angel*. He was kind and compassionate but firm.
Lesson: When it comes to a life and death issue, choosing the best hospital makes all the difference.

My chemotherapy treatments were "uneventful." The nursing care at the MSKCC chemotherapy suite was exceptional — a *host of Angels*. I followed their aftercare instructions exactly.
Lesson: Strictly following instructions and hygiene recommendations during treatment is essential.

Losing my hair dropped my self-esteem and self-confidence, so my husband immediately took me shopping for a wig and pretty hats.
Lesson: Looking your best during treatment is inspiring.

When I returned to work, a new manager, who I presume thought that I was not going to make it, cruelly and systematically abused me until she forced me to leave. I made a mistake by not seeking counseling.
Lesson: Don't accept abuse just because you're weak.

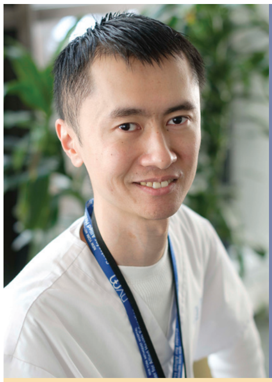
To combat my fear of cancer relapse, it has been essential for me to develop my spirituality and to exercise regularly.
Lesson: Spirituality, physical exercise, and seeking professional help are crucial survival tools.

A handful of friends and relatives were also among my *Angels*. My *Archangels* were my husband and my then-90-year-old mother. Short of going through chemotherapy with me, my husband was by my side at every chemotherapy session. My exceptional oncologist, his team, and a trusted therapist at MSKCC are my *permanent Angels*.

I would like to share with all my fellow survivors an excerpt of a prayer my husband gave me after my last chemo session.

God's Answer

I asked for things that I might enjoy life. I was given life that I might enjoy all things!



Gifting & Receiving

By Cyril Tai

Cyril is a native of Williamsburg, Brooklyn. He holds a BS degree in agricultural engineering and an ME degree in chemical engineering. He is an aspiring medical dosimetrist studying radiation therapy at New York Methodist Hospital.

To give and to receive, it's a coupled process, one that is psychologically rewarding on either end. I think of myself as a giver and as a receiver. I give and receive in hospitals both as a volunteer and as a radiation therapy student. I also received and gave while a patient at Memorial Sloan-Kettering.

As a volunteer, I give time at another hospital. In exchange, the hospital gives me a voucher for a sandwich, fringe benefits like doing yoga with the patients, and the opportunity to gain experience working in a hospital. At first I remember dragging myself to my volunteer assignment, not looking forward to it even though at times it was the best thing that happened to me all week.

Some of the people I've worked with have been bone marrow transplant patients, meaning they were going to be there for at least four to six weeks. This gave me a chance to really get to know them. Among my best times was listening to a man from West Africa tell stories about visiting Montreal and seeing snow and escalators for the first time. Another was buying chocolate ice cream bars in the lobby café for a portly and very delighted patient who couldn't leave the unit. We also commiserated after watching the Jets blow a field goal to tie. Little things. Just letting patients know someone cares.

But volunteering had its drawbacks. There was a good chance that some would not make it. I've had that happen to me. It's unnerving to find out someone you just saw a week ago is gone. It's a splash of cold water, a dose of reality. I used to think what I did didn't matter because the patient died anyway. But now I see that my judgment was hasty. You have to give it a shot even if you think it's not worth the trouble because the trouble may be worth it for that one person.

> I'm grateful for being on the receiving end. But gratitude for my care can hardly be expressed with baked goods or floral arrangements.

They teach you in ethics training that you shall not accept gifts from patients. But they don't teach you about the patients who insist on giving and are insulted if you do not go along. It's like little old Chinese ladies fighting over the tab for dim sum. A number of patients in my clinical rotations have given me stuff. A bottle of sparkling wine. An instant-win scratch-off game. A videotape of a Vegas nightclub act. Cookies, cake, cannoli. It's ironic that in this line of work you're apt to get fat from all the food patients give you.

It sounds overrated, but caring is one of the most comforting things that one can ever receive. Especially if I'm a patient sitting in bed, with my neighbor's TV blasting and my IV drip running low, pressing my call button to no end. I'm grateful for being on the receiving end. But gratitude for my care can hardly be expressed with baked goods or floral arrangements.

On the urging of my parents, when I was a patient I did give two doctors gifts. Coincidentally my dad bought the gifts at a "hospital," the Fountain Pen Hospital. One doctor got a decent pen and pencil set. The other got a nicer pen but no pencil. And the nicest pen was supposed to go to a third doctor, but I didn't like him very much, so I kept it.

Since my own encounter with cancer, I've come to believe that there is good karma that I'm obliged to return. It's the circle of life. Someone helped me, now I help others. Doing something to make their days better. Anything really. Just chatting or fetching a bottle of water. Simple yet powerful.

Treating After Treatment

By Mark Gugliotti

Dr. Mark Gugliotti, PT, DPT, OCS, COMT, CCES, received his initial degree in physical therapy in 1995 from the Hogeschool Enschede, in the Netherlands. He works for a local Long Island hospital where he has been assisting his patients in achieving their rehabilitative needs for more than ten years. Mark lives with his beloved wife, Irma, in Wading River, New York.

As a physical therapist, I'm constantly meeting new patients seeking my services to help them recover from whatever ails them. Over the years, I've learned many skills that have aided me greatly, but none as important as listening. Patients will often come to the office with a litany of concerns and quandaries, hoping someone might finally listen to them.

That's where I come in. Initially, I help patients to understand the complex things happening inside their bodies. After that, we develop a game plan that will help them get back to their normal routines. Not too long ago, I had the good fortune of being diagnosed with cancer. I know that sounds rather absurd, but it's true. As I underwent the barrage of tests and treatments, I had the pleasure of meeting many others just like me. I found myself intrigued by each person's story of how he or she was getting through the cancer. And while each person's experience was unique, I couldn't help but notice that there was a lot of overlap. In many cases, his or her needs were very similar in nature to those of my own patients, so I felt right at home. This was the good fortune part.

As I listened to them, I found that I was able to share my own personal experiences and offer advice that many found both helpful and comforting. These casual conversations would happen in waiting rooms, treatment areas, and even locker rooms, where the only thing between me and my neighbor was our thin cotton gowns.

Realizing the positive impact of these conversations, I recently began providing physical therapy services to cancer survivors. With only slight adjustments to interventions our clinic currently provides, we are better able to serve the needs of this highly motivated population. For me, it's like starting my fourteen-year career all over again. I'm able to connect with my patients in an entirely different way. Whether we commiserate over the trials we muddled through or celebrate our survivorship, one thing is for certain: the program goals for each patient remain the same — independence and empowerment. Since the program's start, I've assisted a man in returning to his love of golf following prostate cancer. Through strength, endurance, and balance training he's now able to enjoy a full round of golf without fatigue. I've also encouraged a woman back to her passion of art after ovarian cancer. Through the use of hand-strengthening and dexterity exercises, I helped her manage the neuropathy she developed during her cancer treatments, enabling her to work in her art mediums of choice.

It's such a wonderful experience to see the transformation back to health happen right before my eyes. It also serves as a reminder of just how far I have come with the help of Memorial Sloan-Kettering Cancer Center.

Running with Luck

By Tim Rossi

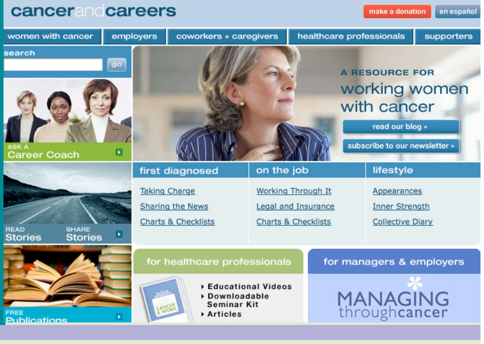
About 15 months after radiation and just after turning 51, Tim completed his first marathon. He lives and runs in Westchester, New York, with his wife and daughter.

It's six a.m. and I'm in a hotel lobby waiting for my sister and wondering where we'll find coffee. Outside, exceptionally fit-looking runners are already heading over to the start of the Philadelphia Distance Run, the half marathon held there each September. I have not run

■ *Continued on the back cover*

Resource Review for the Cancer and Careers Web Site

By Duane Bailey-Castro



The Internet is a rich and ever-growing resource for information and help for survivors and their families. Web sites have sprung up focusing on a variety of topics important to the cancer community, such as treatment information, survivorship, fertility, and educational scholarships. The growth of blogs and online journals has also added a much-needed human element to this cyber world. However, within this vast virtual universe there has been surprisingly little devoted to a critical topic for the cancer community: employment and the workplace.

The Web site Cancer and Careers (www.cancerandcareers.org) was created to address this very need. Established in 2001 by the CEW Foundation, the charitable wing of Cosmetic Executive Women, Inc., a nonprofit trade organization of 4,000 executives in the beauty care industry, the Web site was a response to the startling realization that a number of its own board members had been diagnosed with cancer and continued to work during or after treatment. Seeking to educate and empower not only survivors and their families but also employers, co-workers, and healthcare professionals, Cancer and Careers helps visitors to the site navigate the often stressful and frightening maze of cancer and employment.

Although any survivor searching for information related to their job will find Cancer and Careers very useful, women are its primary audience. For example, the "Women with Cancer" section lists a number of articles on subjects such as ways to find hats and wigs for women experiencing hair loss, how to use makeup and cosmetics after treatment, and ways to improve and care for nails. A wonderful feature of the Web site is its interactive "Collective Diary," where visitors can ask working women with cancer questions about their experience. However, its most valuable feature, regardless of gender, may be its "Paperwork" section, where one can find invaluable information on legal rights in the workplace, health insurance, HIPAA, filing for disability, and financial assistance.

Organized in a user-friendly manner, Cancer and Careers is also available in Spanish. The Web site offers a variety of free, downloadable publications, too, including tips on how to balance work and treatment, statistical research on the challenges faced by working women with cancer, guides on health and fitness, and cancer support services.

Cancer and Careers is a welcome resource to the online cancer community. Survivors and their families will surely benefit from its rich variety of tools, guides, and links, and so will employers, co-workers, and healthcare professionals.

■ *Continued from page 1*

signed up for a weight-loss program to assuage any fears I had about weight gain, and shifted my social circle so I initially spent less time with smokers and more time with non-smokers who supported healthy behavior.

The third thing I had to do was to change how I viewed life as a non-smoker. In the past, when I had quit I viewed it as a loss or a sacrifice. I was a smoker that was depriving herself of cigarettes. This time I knew I was meant to be a non-smoker, and I figured out that each day I lived with this identity I was being given a gift. No more feeling and smelling bad, shame and secrecy, wasted money or wasted time, and no more being a victim and a slave to something that would only help me become a cancer patient again.

Occasionally I do still get an urge, and sometimes I do wish I could smoke just one or two again. Most of the time, I don't think about it at all. There are things I lost to cancer, but cancer also allowed me to give myself an incredible gift. It allowed me to re-create myself and to regain control over a body that had seemed to betray me. The truth is that it wasn't nearly as hard as I thought it would be. I just needed a little help to find a way that worked for me. I am a non-smoker; and these are words that make me beam with pride.

Continued from page 6

13.1 miles in years, and I am overcome with doubts about my readiness. Retreating to the lobby I can't help thinking, "Why am I doing this?" But when Patty gets off the elevator wearing a LIVE**STRONG**™ cap that matches one she'd given me I remember: I am running because I'm 50 and I have cancer.

I wasn't always 50 and I didn't always have cancer, but two weeks before Christmas 2007 I noticed something on my right testicle. I was concerned enough to schedule an appointment with my internist who was concerned enough to schedule a sonogram. A few days later I circled the parking lot thinking I'd be out in no time and maybe even do some holiday shopping before work.

That's not what happened.

After the sonogram I met with a surgeon who told me something about a spot that had something to do with a growth, something to do with a tumor, something to do with cancer. It had nothing to do with Christmas shopping, and I couldn't understand how that had anything to do with me.

But it did and moments later I was in an empty office, frightened, embarrassed about what surgery meant, trying to figure out how to tell my wife, and wondering why the doctor said I was lucky. I got a second opinion and had surgery two days later. I consulted with an oncologist and came to MSKCC for radiation therapy.

I turned 50 a few weeks after radiation — a rather sluggish 50 since I somehow gained weight during treatment. Running Philly was my sister's idea. She'd run it when I lived there, and, she pointed out, it was the nine-month anniversary of my surgery. With boxes full of win/place/show medals from various races it was nothing to her, but at the time I felt unable to run even three miles.

Encouraged, as always, by my wife and challenged by my eight-year-old daughter, who could now almost outrun me, I started adding miles to my morning jogs. Maybe it was nice to be in control of something, maybe it was nice to share my progress with a few supportive friends, but the miles started coming more easily. The day I finished a 10k in less than an hour (59.41) I signed up for Philly.

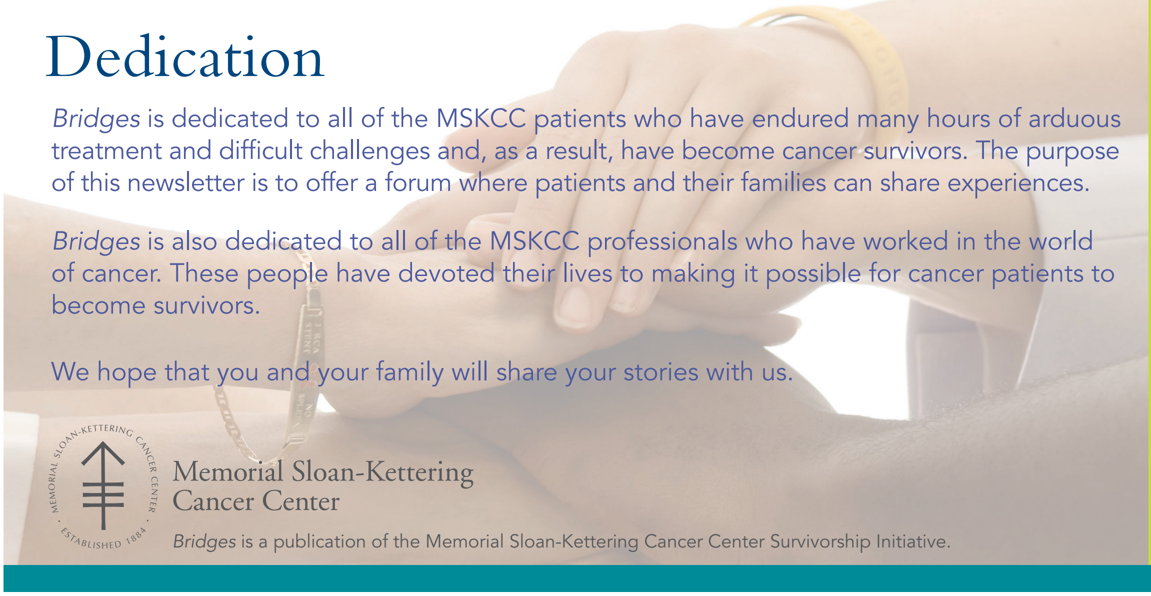
A few weeks later I was standing in that hotel lobby wondering what I was in for, but by then I'd figured out that we never know what the next two hours, or the next two years, will bring. It was a beautiful morning and I was cancer-free, and come what may, I really was starting to feel lucky.

Bridges is available to read online at www.mskcc.org/bridges.

If you would like to connect with other survivors through the Post-Treatment Resource Program, please see the online calendar at www.mskcc.org/livingbeyondcancer.

We are grateful for the support of our patients and family members. If you would like to be involved in volunteer efforts at Memorial Sloan-Kettering Cancer Center, please consider becoming a Patient/Family Advisor. We ask that patients be at least one year post treatment.

For more information, call the Department of Volunteer Resources at **212-639-8623**.



Dedication

Bridges is dedicated to all of the MSKCC patients who have endured many hours of arduous treatment and difficult challenges and, as a result, have become cancer survivors. The purpose of this newsletter is to offer a forum where patients and their families can share experiences.

Bridges is also dedicated to all of the MSKCC professionals who have worked in the world of cancer. These people have devoted their lives to making it possible for cancer patients to become survivors.

We hope that you and your family will share your stories with us.

Memorial Sloan-Kettering
Cancer Center

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

WRITERS WANTED

We welcome story submissions that will be considered for publication in *Bridges*. To learn more, contact the patient editor at **Bridges@mskcc.org**