

Bridges

CONNECTING CANCER SURVIVORS

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Jill the Pill

By Jill Collins

After surviving two bouts with cancer, Jill wants to help support individuals who have recently been diagnosed.

My nickname is Jill the Pill. I came into this world May 13, 1961, born the middle child of five daughters. We were raised in Michigan. At age 22, I noticed a lump on the left side of my neck. I was also losing weight, catching viruses, and feeling run down. I saw many doctors. Finally, after about one year of being misdiagnosed, I arrived at MSKCC. I spent a week pretending I was living at a fancy hotel while the doctors did all kinds of major tests. My doctor and two fellows followed me around while we waited for the test results. It was discovered that I had Hodgkin's disease of mixed cellularity stage IIA — three different kinds of cancer cells. I started with chemo (MOPP), four rounds in 22 days. Then I had radiation and another four rounds of chemo. I came out a shining star, so happy to be given a new lease on life. God had a plan for this chick! I was cancer-free for 26 years. I married, had two children, and was loving life. My doctors warned me about late effects of my treatment, so I knew I might have to deal with breast cancer one day.

A breast MRI done at my follow-up visit showed a small tumor that was

hiding out on my right breast — 1.6 centimeters of invasive ductal carcinoma. BUMMER. I put my armor on again and told myself time to fight this battle! I tried to get out of going through chemo again, but ended up needing to have eight rounds of Methotrexate, 5-Fu, Cytosan with a double mastectomy to boot.

My heart really leads me into advocacy work and helping others down a path of recovery and healing. I was recommended to serve on a panel for the Department of Defense congressionally directed medical research programs. I tell my survivor story on the LIVESTRONG Web site for the world to view and am a "Bridges Breast Cancer" volunteer who spoke at Relay for Life. I would like to go back to school to finish a nutrition degree so I can help others with their health issues and staying cancer-free. My one wish would be to have our research move along faster and come up with much better ways to stop cancer in its tracks. Thanks for tuning in to my story. I hope it will help others go down this road a little more easily. Have a Sparkling Day.

— Jill the Pill

In this issue

- 2 Editorial & Cancer Warriors
- 3 Ask the Professional
- 4 Significantly Altering Moment
- 5 Resource Review
- 6 Life's Curve Balls
- 7 Ask the Survivor
- 8 Dedication

If you are interested in
submitting your story,
please visit

www.mskcc.org/bridges



Memorial Sloan-Kettering
Cancer Center



Bridges has become a voice for MSKCC survivors willing to share their stories and personal experiences through the journey of cancer, which can take a person from patient to fighter to survivor. Being a “survi-

vor” means different things to different people. Some survivors still face many health challenges. Certainly not everyone feels they are the same person they were before their illness and not everyone copes in the same way afterward. While cancer and the requisite treatments can strip people of their past selves, survivors are resilient and determined. Even the word survivor can mean different things to different people. It can resonate with some in a positive way yet irritate others who don’t want to be classified as a subgroup just because they have survived cancer and its hard-

ships. The medical community is recognizing that the transition after treatments have ended is an important phase that requires support.

In this issue, we review a resource called Imerman Angels, which was started by a young cancer survivor who turned his own experience into a service that provides emotional support to others going through the difficult challenges. Often cancer survivors feel the need to give back after their own experience, and fortunately cancer advocacy is a growing field as we transition into *Living Beyond Cancer*.

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



Cancer Warriors

By Patrick Egan

Patrick lives with his wife, Michele, and daughter, Megan. He has been a District Business Manager at Pfizer for 19 years. He enjoys coaching girls’ softball, playing men’s softball, and spending time with family at the New Jersey Shore. He recently finished six months of chemo and is happy to report that there are now no signs of cancer.

Ienjoyed the article by Jonathan Edelstein in the winter issue of *Bridges*. First I want to say how happy I am that Jonathan is doing so well. He has an optimistic attitude and is truly a warrior!

I want to let him know that he is not alone. In the early 1970s, I too was diagnosed with acute lymphoblastic leukemia. I was about three years old at the time, and treatment options were mostly experimental. I too did not really realize the significance or the reality of what was happening. All that I knew was that we had to make many trips to Memorial Sloan-Kettering

and spend a lot of time out of school (there were some advantages).

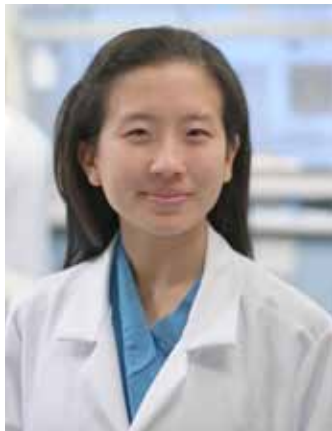
Treatment was not easy at the time; sometimes it was downright scary. Spinal taps and bone marrows were my least favorite, but as long as I knew step-by-step what the physicians were doing I was OK.

The time I spent being treated helped me learn many lessons in life. First, I refuse to say never. Not too long after I was married, physicians said that I would never have a child based on the treatments I had when I was young. I truly felt that if I survived cancer there was nothing I could not accomplish. After much research, finding physicians that were willing to take a chance on the old premise “if they could send a man to the moon . . .” I

was able to father a child.

In spite of my personal obstacles, I was able to turn my positive outlook into a very successful sales and management career. I not only use my story for my personal development, but also share it with others so that they can take what I’ve learned and apply it to their own life’s obstacles.

Today, at 40 years of age, all my previous life lessons and inspiration from other cancer survivors are helping me get through my next battle. In June 2009 I was diagnosed with cancer of the appendix. It was hard at first wondering “why again,” but as I thought back on how I was able to overcome so many obstacles I truly understood the why . . . because I can overcome it! Like Jonathan Edelstein, I am a warrior!



Christine Liang, MD

Ask the Professional

By Christine Liang, MD, Kishwer S. Nehal, MD, and Kevin Oeffinger, MD

Dr. Christine Liang is a dermatologist and the Mohs Micrographic Surgery fellow at Memorial Sloan-Kettering Cancer Center and New York University. Dr. Nehal is a board-certified dermatologist with fellowship training in Mohs surgery, dermatologic surgery, and laser surgery. She specializes in the treatment of early-stage melanoma and non-melanoma skin cancers. Dr. Oeffinger is a primary care physician and director of MSKCC's Adult Long-Term Follow-Up Program.

Q Do cancer survivors who have undergone radiation treatment have an increased risk of skin cancer?

A Skin cancer arises due to a number of different factors. However, there is a higher risk of skin cancer in patients who have had prior radiation treatment, with skin cancers typically developing nearly 20 years after treatment. When radiation treatment targets a specific body area, the risk for skin cancer is generally limited to the radiation site. Patients who have received total body irradiation can develop multiple skin cancers over time. Individuals who were treated for a pediatric or young adult cancer in the 1960s and '70s are at an increased risk. It is very important to note that studies suggesting an increased risk for skin cancer related to radiation treatment are based on older treatment protocols. Today, our radiation oncologists use sophisticated technology and targeted dosing parameters along with quality assurance programs to effectively and safely deliver radiation while minimizing the risk of developing skin cancer.

Q What are other skin cancer risks that survivors should know about?

A The most common risk factor for skin cancer is excessive sunlight or ultraviolet radiation exposure in an individual with red or blond hair and fair skin that burns or freckles easily. Multiple risk factors or carcinogens can play a role in skin cancer development and are outlined below:

- Chronic sun exposure and a history of sunburns
- Use of tanning beds
- Having many moles or abnormal moles called dysplastic nevi
- A personal or family history of melanoma
- Immunosuppression, which includes individuals with a history of HIV or leukemia/lymphoma as well as treatment with immunosuppressant drug therapy for reasons such as organ transplantation

Q What kind of screening plan should be developed for a cancer survivor who has undergone radiation treatment?

A If you have any of the risk factors for skin cancer, you should speak to your healthcare provider about

the value of a complete skin examination. Any signs or symptoms of skin cancer should be brought to the attention of your physician. Signs of skin cancer can include scaling, oozing/bleeding, persistent irritation, and any spot or bump that changes in color, shape, or size, or becomes painful.

In order to reduce skin cancer risk, we suggest that survivors limit exposure to ultraviolet radiation from the sun or tanning booths. This can be accomplished by reducing time spent in the midday sun (between 11:00 AM and 3:00 PM) and by wearing protective clothing and accessories, such as wide-brimmed hats, long-sleeved shirts, and sunglasses. A broad-spectrum sunscreen with SPF 30 should be applied generously before going out, even on cloudy days, and should be reapplied after swimming or perspiring. The good news is that if skin cancer is detected early it is usually very treatable.



Kishwer S. Nehal, MD

Significantly Altering Moment

by Lisa D'Ottavio

Lisa lives in Pawling, New York, with her husband and two children. She is a three-and-a-half-year breast cancer survivor. She spends as much free time as possible writing and would love to make it a career when she grows up!



A few years ago, I was asked to write about my most significantly altering moment. I thought it would be difficult at first, so I decided to define “significantly altered.” So many *significant* moments and days crossed my mind when I really thought about it.

I looked for a synonym and “meaningfully changed” was the phrase that resonated with me. I wrote a list of days rather than identifying one specific moment. In no particular order, I came up with the following:

- diagnosis day
- surgery day
- my wedding day
- the day(s) I gave birth
- the day my grandmother died
- September 11th

I looked at the list again and noticed what I had written first. I guess I had my answer. On diagnosis day, I first heard the news that I had cancer. I will remember that day for the rest of my life, and as much as I wish that it hadn't happened, it was undoubtedly the moment that significantly altered my life. *Forever.*

It was a warm August Monday. August 14, 2006, to be exact. The air conditioning had been blasting for two weeks. I was dreading the electric bill, of all things (how insignificant that seems now). I had had a biopsy done on the

Thursday prior and then had enjoyed a great family-and-friend-filled weekend. My life felt perfect.

I can't have cancer. I have too much to do. I don't have the time, the money — I need to go back to work in September, and I have that babysitting job with the neighbors all lined up — everything is set.

I was on my computer when I got the phone call.

“Are you alone?”

And, of course, I was. My husband had come home early from work and was at the community pool with our son, and my teenage daughter was out with friends. I wasn't expecting a call so soon...

Her next words halted me. But she spoke so slowly and so mechanically, I knew I had heard her correctly.

“Your biopsy shows that you have breast cancer.”

“Huh?” I stopped what I was doing.

I think that I actually stopped breathing for a moment. I fell into the nearest chair while the *word* went swimming in my head. I felt helpless, shocked, so incredulous, and in such disbelief that I couldn't breathe or speak. The doctor must have sensed all of this.

“Are you all right?”

I finally got some mangled words out. “Uh, yes, uh, thank you for calling me so soon.”

“Thank you?” What was wrong with me? Well, apparently, something definitely was...

“We will call you tomorrow with what you need to do next.”

She added, “You need some time to let this...sink in.”

Ya think?

I hung up and immediately called my husband's cell phone, but of course, he had no reception at the pool. I must have left a horribly garbled, strange-sounding message because he and my son crashed through the door ten minutes later. They found me sitting in a heap on the floor. I told them what the doctor had told me. The moment was surreal. We all just started to cry and held each other, moaning. I was in a nightmare, and I prayed that I would wake up from it. I sobbed and held on to them for dear life. *Dear life.*

The moment when I didn't wake up from the nightmare was *the* most significantly altering moment of my life. I knew I was certainly and irrevocably, *meaningfully changed.*

Resource Review By Eileen F. Gould

IMERMAN ANGELS: One-on-One Cancer Support: Connecting Cancer Fighters, Survivors, and Caregivers



through this program they can do so by connecting with someone going through the same thing. It also pairs caregivers of patients with caregivers who understand from previous experience what it is like helping a loved one.

To make the matches, a representative from the organization meets with the patient or caregiver in person or over the phone and searches the organization's database for the survivor who is most like the fighter based on factors such as cancer type, treatments, age, gender, and geography. Geography does not limit the relationship, as the patient or caregiver may never meet their Angel in person, but may develop a telephone or e-mail relationship. Or if they live near each other, they may meet in person; the Angel may even, for example, go with the cancer fighter to his or her first chemotherapy treatment. As of now, Imerman Angels has connected more than 2,000 cancer survivors (Angels) with current cancer fighters by partnering with hospitals, oncology nurses, social workers, and doctors. On a weekly basis they connect 25 to 40 cancer fighters to cancer survivors for one-on-one support.

Imerman Angels does not turn anyone away, and their services are free of charge. Their Web site is www.imermanangels.com, and their phone number is 866-IMERMAN or 312-274-5529.

Have you ever wanted to talk to another cancer patient who has been through what you have been through, but you did not know how to find someone? Imerman Angels is a not-for-profit organization that connects a person fighting cancer with someone who has survived the same disease. The organization is based in Chicago; however, they connect people throughout the United States and around the world. Their mission statement is "Imerman Angels provides personalized connections that enable one-on-one support among cancer fighters, survivors, and caregivers."

Imerman Angels was founded by Jonny Imerman, who is a survivor of testicular cancer. During his own experience as a cancer fighter, he realized how many people had no one to support them, so he created an organization so that no one would have to fight cancer alone. The relationship provides the cancer fighter with the opportunity to ask questions and to receive support from someone (an Angel) who has been through a similar experience.

It is common for cancer survivors to feel the need to give back, and



Life's Curve Balls

By Matthew A. Peene

Matthew is 21 years old. He enjoys volunteering, playing his guitar, listening to music, and spending time with his family and friends.

I was far younger than most people who get cancer when I was diagnosed with a malignant brain tumor called medulloblastoma. When I was diagnosed, I was about six years of age. Within a year, I was treated with three brain surgeries, chemotherapy, and craniospinal radiation, and I had a ventriculoperitoneal shunt placed in my brain for hydrocephalus. When my body functions began to shut down, I became paralyzed. My whole left side and my lower body were completely useless. Even with long hours of physical therapy, the doctors still came to a conclusion that I would never walk again. But through my hard drive and the inspiration of my family and friends, I slowly recovered and began to walk again. I went from a wheel chair to a walker, and then finally I began to walk again. Through my experiences in life, I came to the conclusion that I wanted to help cancer patients and anyone else who has any physical illness. These doctors saved my life, and now it's my duty to help others like me.

Having been diagnosed with medulloblastoma, I was forced to change dramatically. Not only did these three extremely intense years sentence me to extreme medical procedures to cure me from my cancer, but in subsequent years I was confined in other ways. I could never do the majority of activities that the rest of the world could. My limits were drawn with a very obvious line. Not only were the chal-

lenging effects affecting me but also the rest of the family. My family had to cope with my slow recovery and the continuous check-ups at Memorial Sloan-Kettering Cancer Center, a three hour drive one-way from my home in Pennsylvania. While my mom, my dad, and I went up to New York, my two brothers stayed with my grandparents, causing a continuous split-up. Even when we were together, our medical bills were so high that we couldn't have any family vacations. The hospital experiences have brought about a metamorphosis in my life, including my mind and body. While in the hospital, I made close friends, who were treated similarly. Unfortunately only about 10 percent survived their sicknesses. Slowly losing friends to a devastating disease killed me inside, and it inspired me to assist others. As young as I was, I wanted to take on the task of lifting others' spirits up. I admired the doctors and nurses who worked passionately to help the children survive their own malignant diseases.

Now I'm free of the disease, thanks to all the men and women who stood by me while I was sick. I'm miraculously back to my original self. Though I was confined to a wheel chair, I beat the odds and am now playing guitar and am a goalie in a roller hockey league. All the hard work and patience that it takes to cure a suffering person motivates me and excites me to further their innovations. Seeing all of those brilliant men and women with their extraordinary skills to save lives made me realize that I want to devote myself to the medical field.

I made plenty of friends, both patients and professionals during my days in the hospital. I would like to think that it's because of my personality and positive attitude. I remember being in Hershey, living in a bed. Now if you knew me you'd already know that's not how the story ended. I found that it's still possible to have fun and a sense of humor, even in the hospital. I would have the whole wing up and out of bed with my famous water gun fights that involved nothing more than 50cc syringes and a bed pan full of water. Here are these kids with IVs going up and down the hallways having a water syringe fight, even with the nurses there, or playing soccer in those small halls of Hershey. Old times of calling my friends on the phone when they were only a few doors down the hall and just jamming to Def Leppard on my Sony stereo, and the nurses would come in one by one wanting to listen too. A few friends and I even started a band, singing about how they have you peeing in hats. We were good, just couldn't find someone to give us a record deal. These moments I will always remember, a bunch of sick kids with smiles on their face and hope in their hearts. If one person reads this what I would want them to know is that though things are bad it's never too bad to not enjoy life and believe that there will be a tomorrow, and I say that because I know the human spirit is more powerful than the body or any disease.

May the four winds blow you safely home.

Ask the Survivor: Breast Reconstruction



By Beth Schiff

Elizabeth “Beth” York Schiff is a survivor of Hodgkin’s disease (1977) and stage I breast cancer (2007). Born and raised in North Carolina, Beth attended Duke University for undergraduate and law school, and has practiced law in New York and Cincinnati, where she currently lives with her husband and three sons. Beth is an active volunteer for the Cincinnati Cancer Consortium.

As a breast cancer survivor, what decision-making strategies did you find helpful when considering breast cancer reconstruction, and what advice can you offer someone who is going through this process?

When faced with a breast cancer diagnosis, the amount of information to process and the decisions one faces can be overwhelming. The best advice I can offer is to be patient and take the time to learn all you can about your diagnosis and choices before you schedule surgery. I recall that my initial reaction after diagnosis was to schedule surgery immediately. Given the seriousness of a cancer diagnosis, breast reconstruction didn’t even enter my mind. Many well-meaning girlfriends were quick to advise me to “just have them taken off!” After the initial shock, I did find myself compelled to at least consider my options with respect to breast reconstruction. In the end, I learned that serious consideration of reconstructive surgery is an important part of the decision process for anyone faced with this tough choice. Ultimately, I opted for reconstruction and have been very happy with my decision.

Please be patient and allow yourself the time to process your diagnosis and to learn exactly what your surgical options are. If you are considering reconstruction, in addition to meeting with a breast surgeon, you will also meet with a plastic surgeon. Many people find it helpful to talk to more than one breast and/or reconstructive surgeon. In my case, the second plastic surgeon I consulted offered a less extensive method of reconstruction, which resulted in less surgery and shorter recovery. Be sure to determine if breast surgery or reconstruction is the surgeon’s specialty. MSKCC plastic surgeons specialize in

reconstructive surgery and do hundreds of breast reconstructions annually.

Keep in mind that there are multiple ways in which your breasts may be reconstructed. Depending on your body type, your medical history, and the outcome you desire, your plastic surgeon will make a recommendation. Consider all options carefully with your surgeons and select the one with which you are most comfortable.

Depending on what type of treatment you will be receiving for your breast cancer, your surgeons will also recommend how best to time your reconstructive surgery. There are some women who prefer to wait until later to consider reconstructive surgery – that is an option, but I would advise you to at least talk to a plastic surgeon at the outset and to consider all options. I was able to have the reconstructive surgery at the same time as the bilateral mastectomies, and although it was a longer initial surgery, in the long run it was one less surgery I had to go through.

Another important aspect of reconstructive surgery is the follow-up with your plastic surgeon and his or her staff. At MSKCC, the day after my surgery I met with physical therapists who instructed me on exercises that greatly helped with my recovery. Likewise, my plastic surgeon at MSKCC has a terrific staff that was always available to discuss any question I had during my recovery.



Jessica Moser was writing poetry before her cancer diagnosis, and is happy to be back doing it again. She has done readings in New York City. She lives in Manhattan with her husband, Eric, and her two children, Jamie and Julia.

Dedication

By Jessica Moser

This is not to honor the anesthesia
they put me to sleep with
or the knife they used
to open me up
and take the cancer out.

This is not to honor the chemotherapy:
the chemicals that swam through the needle
that they had to push into me
because the drugs were so toxic
they'd have eaten through the IV bag.

It is not for the radiation
that they made me lie down for
while they inserted the metal plates,
turned off the lights and left the room
and the machine buzzed and burned
my skin.

It is for my body
sick from the medicine
tired from the poison
for surviving in that dark hole,
for holding this insidious snake of a disease by the neck.

For being able to reach for a glass,
pour from a pitcher,
drink cold water down,
and feel it in my throat, my chest, my belly, spreading,
a slow burst of fireworks on a dark night:
red, yellow, blue stars, everywhere.

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**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.



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