



I Did It By Victoria Pfister Brown

Victoria was diagnosed with medulloblastoma when she was 12 years old. She is now 16, a junior at St. Rose High School, an honors student, and a varsity athlete. She volunteers much of her time with numerous charities.

Cancer Center, where I was treated. He made sure I got the best care possible. I don't know what I would have done if he were not there.

I remember coming home from the MRI in tears because I couldn't go to Florida. (My family and I were planning on going to Marco Island for Easter vacation.) My grandpa and brother were at home waiting and I remember tears filled my grandpa's eyes; I thought he was bummed about not being able to go to Marco Island. I packed some clothing and my parents and I headed to New York City.

We arrived at NewYork-Presbyterian Hospital where I had my surgery. Stickers were put on me and attached to machines. I was put in bed and was awake for a really long time. I was walking with the nurse that night, and

he asked me, "Do you know what's going on?" I said, "No, not really." He responded, "You're getting brain surgery tomorrow." My dreams of going to Marco were getting hazy.

As I lay in the hospital bed, the doctor was telling me all this "stuff." He asked if I had any questions. I asked how long the surgery would take and if it would hurt. He said the surgery would be six to seven hours and it wouldn't hurt. I turned to my mom and said, "We can still make the train!" Boy, was I wrong. I didn't think about recovery or what was soon to come.

In the weeks following my surgery, I got a Medi-Port put in me for easy access to chemo. Chemo was very long and tedious, as was radiation. Luckily for me I had outstanding nurses and

■ *Continued on page 5*

So many doctors, so many months of not feeling well, one doctor suggests an MRI, the brain tumor is found, and my story begins. I was diagnosed with medulloblastoma on April 2, 2007. It is a type of pediatric brain cancer.

My Uncle David, also my godfather, works at Memorial Sloan-Kettering

In this issue

- 2 Editorial & Us Too
- 3 Ask the Professional
- 4 Keep the Faith
- 5 Resource Review
- 6 54 Years and Counting
- 7 Ask the Survivor

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Memorial Sloan-Kettering
Cancer Center



Before cancer, most of us were on a track — we didn't know the exact final destination, but we had an idea of the direction and speed we were traveling. Cancer derailed our personal journey, and we came to realize that a planned existence was not guaranteed.

Survivorship requires a difficult transition from a state of illness to one of well-being.

Cancer is a challenge to our plans and dreams and impacts our emotional and physical resources and even our financial health. It is difficult to adjust to the loss of control that cancer presents. We have all heard

that maintaining an optimistic and hopeful attitude is crucial even though a sense of balance has been lost.

Even though one may achieve a physical cure, the healing process continues for a long time, sometimes forever, and new strategies may emerge. Some survivors may become more spontaneous rather than living a previously planned existence. As a result, some of us might even discover the "simple pleasures" (see back cover) that may not have been on our radar screen before.

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

Us Too By Kirk Royster

Kirk is a health educator, an HIV/AIDS counselor for a nonprofit dealing with homeless populations, and a member of the American Association for Cancer Research. He lives in Brooklyn with his wife and enjoys baseball and bowling.

“To know the road ahead, ask those coming back.” As I rode on a crowded subway train recently, this Chinese proverb plastered on a billboard caught my eye and I reflected on my battle with prostate cancer.

Last fall, I was only 43 years old, my doctor never felt anything unusual during a digital rectal exam that was part of my annual physical. But being an African American and having an uncle with prostate cancer put me at a higher risk for the disease, so I took a free prostate-specific antigen (PSA) blood test and moved on with my life...or so I thought.

The result of the test came back suspiciously high for my age and a second PSA was even higher. Suspicion turned into confirmation of prostate cancer after a biopsy. I was scared and driven to find men like myself who could understand my fears and help me make important decisions about treatment.

I found the Manhattan chapter of the Us TOO prostate cancer support group online and called group leader Jack

David Marcus. He warmly welcomed me to “the club.” He asked about my doctor’s visits and lab results, but was mainly concerned about my emotional state. As we ended our first conversation, he invited my wife and me to Us TOO’s monthly meeting.

I attended that first meeting alone, sat nervously through the guest speaker’s lecture, and then introduced myself to Jack David. He greeted me before leading the group, where patients, survivors, and their loved ones talked about the effects of prostate cancer on their lives. Every man who spoke was honest about his struggles and successes. While I was amazed by their candor, it was difficult to talk about myself and answer their questions, but I found the courage to open up.

As the months passed, it was easier to share with the group, and I took control of the fight against my disease. The guys and their loved ones helped me make informed decisions about my treatment. Steve, another group leader, was especially gracious during this difficult time. He shared the immense

body of knowledge he acquired during his own treatment and suggested ways to deal with common surgical side effects.

The greatest and most unexpected by-product of attending the meetings is the genuine friendships I’ve made. My new friends checked on me after surgery and, even today, support me in other aspects of my life. As our relationships grow, we discover common interests far from what initially brought us together.

Even though recent blood tests reveal that all of the cancer has been removed, I am still learning to be patient as my body slowly regains continence and sexual potency. The toughest part of my cancer journey is behind me, yet my dedication to my Us TOO group has deepened. As a new prostate cancer advocate, I am meeting other cancer fighters and learning about the latest research. I strive to “pay it forward” by helping newly diagnosed men tackle their disease. As the Chinese proverb goes, I’m on the road, but instead of looking ahead, I’m coming back.

Ask the Professional

Changes in Skin, Hair, and Nails After the Completion of Cancer Treatment

By Dr. Mario Lacouture

Dr. Lacouture is a board-certified dermatologist with special interest in dermatologic conditions that result from cancer treatments. His clinical career has been focused on the recognition and management of side effects affecting the skin, hair, and nails of cancer patients and survivors.



Q Now that my cancer treatment is complete, my hair is growing back. However, the texture is different. I have also noticed changes in my nails. Is this normal?

A Many people report that their hair loses its color or becomes more brittle after cancer treatment. This could be due to the chemotherapy

drugs causing permanent damage in the hair-forming cells or in the cells that give hair color. In cases such as these, you may color or dye your hair to the shade it was prior to treatment and your doctor may recommend biotin (2.5 mg a day) to rejuvenate brittle hair. Your nails may change when treated with classes of drugs known as taxanes or antimetabolites. Both fingernails and toenails can be affected, especially after several cycles of therapy. The symptoms of nail changes can range from dark discoloration to nail separation with pain and secretions. Keep your hands and feet well moisturized with creams or ointments. It is OK to use nail polish, but avoid pedicures at salons when you are receiving treatment. Your doctor may recommend biotin (2.5 mg a day) for brittle nails. If symptoms persist you may want to consult a dermatologist. Finally, certain topical formulations such as minoxidil (for the scalp, available over the

counter) and bimatoprost (for the eyelashes, available through a prescription from your doctor) can be used to speed up regrowth during treatment.

Q I am thankful that my surgery went well, but I wish my scars were less noticeable. What are the best remedies to reduce scarring?

A Whether a scar develops and how it heals depend on several factors, such as how deep and how big the wound is as well as where in the body the injury is located. Scars can be more disfiguring in hair-bearing areas, such as the scalp and, in men, the chest and extremities, as hair does not usually grow within a scar. Other factors that may affect how skin reacts to surgery include a person's medical condition or history of radiation, nutrition, wound infections, skin color, ethnic background, and even age. Furthermore, smoking as well as certain illnesses (such as diabetes) can also slow the healing process.

Medical studies have shown that scarring from surgery has been linked to psychological problems in about 15 percent of survivors of childhood cancer. Also, many women with breast cancer, especially younger patients, have found it difficult to adjust

psychologically to their scars from mastectomy. The good news is there are several ways available at MSKCC to reduce the size and appearance of a surgical scar including:

Laser surgery. A laser (or light) removes the outer layer of skin or blood vessels and allows new, firmer, smoother skin to form at the site of the scar.

Injection. A corticosteroid or a chemotherapy drug (fluorouracil, bleomycin, mitomycin C) can shrink and soften hypertrophic scars or keloids. Collagen, a protein that supports the skin, is injected into the skin to fill in dimpled scars. In both cases, the idea is that the surface of the scar is made even with surrounding tissue. Results may last from a few months to several years, and injections may be repeated.

Topical medication. Gels or creams are applied directly to the surface of the skin. They help the skin heal from the original surgery.

Sometimes a single treatment can significantly improve the look of a scar. In other cases, a combination of approaches may offer the best results. Consult with a dermatologist or plastic surgeon to find the right one for you.



Keep the Faith By Patti Lucas Dempsey

Patti was born and raised in Philadelphia. She has two grown children, three grandsons, and a new baby granddaughter. Her interests include her family, faith, and being happy. Her No. 1 hobby is playing golf – if she could, she would play every day.

My journey with sarcoma began the spring of 2006. A few months earlier, I had just turned 50 years of age. Extremely healthy, I power walked every morning and led a clean lifestyle. In May 2006 I had started to have bladder control problems on my walks and my belly was a little puffer, as I put it. My doctor's top concern at the time was treating me for a urinary tract infection, which I didn't believe was the problem, so on to doctor No. 2. He ordered many tests, one of which was a pelvic ultrasound, which showed a very large pelvic mass. On to doctor No. 3: He was a surgeon and suspected the mass to be a fibroid tumor. I was scheduled for a complete hysterectomy on August 1, 2006.

This is when I first heard the word sarcoma. My diagnosis was "liposarcoma," a cancer that grows in muscle, fat, and connective tissue. I was in shock: Cancer that grows in your fat? I am not fat!

On to doctor No. 4, who just monitored me with CAT scans every four months. I tried to live my "new" normal life. I went back to work and was a mom and mom's mom to my three grandsons. I started to exercise

and play golf again. Then the sarcoma showed up again.

Now it's June 2007 and my doctor at the time would not operate, saying the tumor was too large and the surgery too risky. Chemo was the only option he gave me — I was numb. My only daughter was getting married in four months. I was busy planning her special day; this was not happening. I felt and looked healthy. Only one part of me was sick — my belly. What was I going to do?

Through prayers, my continued faith, and knowing the right people, I was directed to doctor No. 5, a brilliant MSKCC surgeon who is a leading expert in sarcoma.

My second surgery was July 10, 2007. My tumor was 31 centimeters, but my doctor was able to get it all with clean margins. I spent ten days in the hospital with the BEST nursing care ever. I can't say enough about the nurses on the 15th floor — unbelievable care and compassion. In about two months, my life was back on track again, but unfortunately, it came back again.

My third surgery was March 10, 2009. It was not too bad, but I started to feel that I'd taken five steps forward and four steps back. I started to realize that this sarcoma is a pesty disease. I got over it yet again, but like the pest it is, it showed its ugly head again.

My fourth surgery was June 15, 2010, and I am now recuperating with my parents at the Jersey Shore, no better

place to be surrounded by so much love and wonderful care.

This is not a sad story; it is a story of survival and strength and faith. Because of sarcoma, I have learned to live my life with more meaning and purpose and have met many nice people along the way. Since my diagnosis, I have gotten involved with an organization, "Peter Skelton Sarcoma Research Fund," and do their walk/run every July during International Sarcoma Awareness Week. I have had many friends and family members (and as the oldest of six kids my family is quite large) support this cause so dear to my heart. This year, the money I raise will be given to MSKCC for liposarcoma. I am so thrilled and hopeful someday there will be a cure.

After four bouts with this disease and my three stays at MSKCC, once I am better, I must do something to show my sincere gratitude to my doctor and the nursing staff. I would like to volunteer my time in some way to pay it forward.

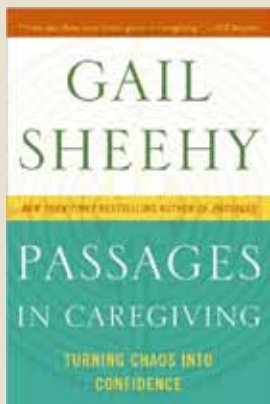
The journey has had its ups and downs. I have had many blessings along the way and for that I am truly thankful.

The best thing I did back in 2007 was get a second opinion because that decision led me to MSKCC for a better chance at watching my grandchildren grow up. For that, I am forever indebted.

God bless each and everyone at MSKCC. Thank you from the bottom of my heart.

Passages in Caregiving: Turning Chaos into Confidence by Gail Sheehy

Review by Eileen F. Gould



Gail Sheehy begins her book by saying that “in almost one-third of American households somebody is serving as an unpaid caregiver.”

This book is a very helpful guide that shares expert advice on caregiving for family members and provides information on everything from advocacy groups to resource guides and strategies. The author relays her personal journey caring for her husband during his 15-year battle with four bouts of cancer and coping with his death in 2008. Ms. Sheehy was married to

Clay Felker, founder and editor of *New York Magazine*.

In addition to drawing from her own experience, she interviews other caregivers as they go through various phases of taking care of a loved one, beginning with initial diagnosis to the patient’s final days. Sheehy offers many resources one can tap along the journey. For example, she suggests that a health advocate can help to navigate the particular health issue so the caregiver is not depending solely on the Internet for information, which may offer only the worst-case scenario. Ms. Sheehy advises not to rush into any major medical decisions, but to carefully weigh all the options. Additionally, she offers suggestions for how siblings can work together to care for their parents and coping

mechanisms to deal with the role reversal that might come about between parents and children.

Furthermore, she recommends that caregivers attempt to maintain their own lives as much as possible. Connect with friends even if it is just a phone call or an e-mail. Assembling a “circle of care” not only among family but within the community will help caregivers from feeling isolated.

Caregiving is very challenging and can take a toll on those providing the care. The book offers very helpful suggestions as to how to manage the many challenges one faces in the role as well as terrific resources, all in one book.

■ *Continued from page 1*

doctors to take care of me. The nurses at Memorial Sloan-Kettering are so perky and always put a smile on your face. In radiation, Sonja took care of me and always told me that I was doing a great job.

Out of the hospital, I received many presents that I was very grateful for from my school, H.W. Mountz; my CCD class, St. Catherine School; family; friends; and my parents’ co-workers. I also got letters from my friends at H.W. Mountz, St. Catherine, and St. Rose High School. I read every single one of those letters; the letters comforted and encouraged me to continue.

My last week of treatment was around Christmas time. My friend from H.W. Mountz, Meghan, organized a fundraiser called Lights On for Tori. People bought orange light bulbs and put them in their outside lights. I was driven around in a fire truck with my friends on the top of the truck and saw all the lights. When we would pass a house with an orange light, the sirens would go off. People made signs for me and were outside waving; it was a great way to kick off my last week of chemo.

I remember sitting on Santa’s lap, and he asked me what I wanted for Christmas. I said, “To be better.” He responded, “Is that it?” I said, “Yes.”

Guess what? It was the best Christmas ever! I finished my treatment and most of my extended family came down for Christmas dinner. Our dining room table was as full as it could get. We were all very close, and I loved every minute of it. That Christmas morning I could stand up by myself. It was truly the best Christmas ever!

Now I am going to be a junior at St. Rose High School. I am teaching tennis this summer, and I play tennis just about every day. I am so happy I am able to do that. Thank you to all my doctors, nurses, friends, and family for helping me and saving my life!



54 Years and Counting

By John DeVescovi

John is a 54-year-and-counting survivor of Hodgkin lymphoma. He is retired from manufacturing ladies coats and suits and currently lives in Bayside, Queens.



To quote the famous New York Yankee Lou Gehrig, I too feel like “the luckiest man on the face of the earth.” I was 21 years old, lucky and fortunate in so many ways; however, I discovered a large lump on the right side of my neck just above my collar bone. I consulted three doctors and was directed to Memorial Sloan-Kettering Cancer Center.

I did not have medical insurance, so back then I was issued a clinic identification card and was examined each week by a different doctor. These doctors donated their time to cancer patients, and I was receiving the best possible care in the world. There was the usual course of examinations, blood work, x-rays, and tests. Finally, a biopsy of the lump on my neck was taken and the diagnosis was Hodgkin’s disease. The doctor took a red marker to block out the areas on my neck and chest to be treated with radiation. Years later I read the doctor’s obituary and discovered my doctor was a pioneer in the development of techniques for the treatment of lymphomas and leukemias with radiation.

I received 30 treatments beginning in December 1956 and seven more three months later. Except for some normal mild radiation burns and temporary loss of strength, I fared very well. I went to see the doctor once a month for the first year to have exams and follow-up. Eventually my visits tapered down to once every three months, then once every six months, and finally once a year.

Each visit filled me with fear and anxiety as I literally held my breath until I heard the words, “You’re doing just fine.”

I met my loving wife of 50 years in September 1959. We were married one year later with the full knowledge that because of my illness there was the possibility of a shortened life together. I have two married daughters

and three very bright grandchildren, but I guess all grandparents say that! Only my immediate family and a few close friends knew of my illness, but that was my choice. The subject of cancer was seldom spoken of as openly as it is today. Support groups and hospital counseling were not available back then.

Perhaps because I did not experience pain and was able to manage a full-time job throughout my treatment, I felt I would not be a victim to my disease. I never doubted that I was in the right place at the right time, and I owe my deepest gratitude to all the dedicated doctors and medical staff at MSKCC. Due to the rapid advances in medical science and technology today, we have more reason to hope and believe there will be greater numbers of cancer patients with success stories like mine.

I prayed for a miracle and I got one! It is almost 54 years now and still counting.

Ask the Survivor: Adopting After Cancer

Q *My cancer treatment has made it difficult for natural child conception. My partner and I truly want to be parents and are considering adopting a child. From your experience, what advice do you have about the adoption process?*

A Adoption is wonderful. It is also difficult, complex, unfair, poorly regulated, heart-breaking, maddeningly bureaucratic, corrupt, and expensive. I hope you'll just find it wonderful, but the truth is you probably won't, until eventually — hopefully — you will.

Let me explain. My wife and I tried to adopt internationally (from Vietnam) and domestically in the U.S. My non-Hodgkin lymphoma survival was a minor factor, though I did have to include details about it on the seemingly endless health forms I filled out. In many programs you're as qualified health-wise as anyone else: You just may need to prove it. Check first because some countries may require that you be in remission for a certain number of years or that you have a physical examination.

By virtue of your survival, though, you've proven you've got the kind of mental endurance you'll need for adoption. The days of easy international adoption are over; programs such as Vietnam, Guatemala, and (at least temporarily) Russia are closing. The



By Michael Solomon

Michael Solomon is a Brooklyn-born writer, filmmaker, husband, and father of two wonderful boys. His childhood babysitter predicted he'd also be the first man on Mars, a prophesy he has not fully abandoned.

wait times in China and Ethiopia are extending into years instead of months.

Domestic adoption is equally tough. If you go through an agency, you'll have a long wait until they match you with a child. Be prepared that it could take years. Alternately, you could go the private adoption route (as we did, successfully) in which you hire a lawyer and place ads in small-town papers. You'll get plenty of responses, some of them promising. Others will be scammers looking to make a fast buck. Still others will be women in the most

desperate situations you can imagine (and pregnant with your potential son or daughter!). Some of the promising birth mothers might change their minds about placing their babies for adoption (in some cases even after you've brought your baby home). The costs range from very, very expensive (\$30,000) to astronomical (\$100,000 and up), so be prepared. However, you should talk to your accountant as you may be eligible to get a huge tax credit or rebate on adoption expenses thanks to new legislation!

Here's an important tip for success: Be prepared to adopt at a moment's notice. Domestic adoptions often happen that quickly. We learned about our son only a day after he was born, and we had to race to Texas within 24 hours so he wouldn't be placed in foster care (from whence we wouldn't have been able to adopt him). Remember, there is no "perfect" situation in adoption; everyone has to decide what variables and risk factors they are comfortable with. You

may not know much about your child's birth parents. But take heart in this: An adoptive child is as delicious and perfect (and imperfect) as any other. Our sweet little boy from Texas is living proof.

Just as everyone's cancer story is different, the same holds true for adoption. You will feel confused by your options and you'll agonize over the uncertainty. You'll rail against the unfairness, but someday, hopefully soon, you'll be looking into the eyes of your new child and all the bad stuff will be behind you.



Simple Pleasures

Having my wife scratch my back and put me to sleep!

—Bob

A swim — 2.4 miles; A bike — 112 miles; A run — 26.2 miles

—David Dorfman

Sunny days in Central Park.

—Rachel



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

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