Bridges

CONNECTING CANCER SURVIVORS

VOL. 23, WINTER 2014

MSKCC as Family

By Christine Barry Furlano

I dedicate this story to Memorial Sloan-Kettering on behalf of my brother, Peter Barry, who was a brave, gentle warrior; his wife Christine; and their children, Denis, Arianna, Kaitlyn, and Jack, whose love lifted him back to God.

Culturally, the country has become inclusive of all different types of families. We see it expressed in movies, in prime-time TV shows, and in print. It seems to me that the driving force and the link that brings all of us different types together – from "Father Knows Best" families, single moms, stay-at-home dads, Dad and Dad, Mom and Mom, and all adoptive parents – is love. We have an unending love for each one of our family members (no matter how much they can annoy you), and we strive to help each other become the best we can be in life.

I have been blessed with an extraordinary adoptive family and second home: the dedicated, loving, and tenacious staff at Memorial Sloan-Kettering Hospital, and the beautiful spa-like Evelyn H. Lauder Breast Center.

I have been coming to Memorial Sloan-Kettering since my breast cancer decided to visit my spine four years ago. I was terrified until I met my calm, caring, and brilliant oncologist. She started me on antiestrogen medicine and sent me to an easy-going and confident radiation oncologist. He administered my treatment while my mind drifted to younger, happier years listening to the Beatles.

My therapist has allowed me to say the words that were stuck in my heart, words I thought I would never recover from once I let them out. She has given me a place to feel safe.

There are many more people who carry out the prescribed wisdom of my doctors: my nurse makes me smile, even when she has to stick me with a long needle. The angel-voiced secretary gets back to me, no matter what, and the woman who walks me to the monthly examination room offers a smile and a compliment.

The art teacher at the Breast Center is a wonderful listener who helps bring out my spirit through my art. *The Visible Ink* program has helped me step out with my words and know that they matter. Every

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Memorial Sloan-Kettering Cancer Center

Editorial

by Eileen F. Gould

The holiday season is a perfect time to say thank you and to express gratitude. This column usually discusses and recognizes the amazing work done at Memorial Sloan-Kettering Cancer Center by clinicians, medical staff, and researchers. As I travel **The World of Cancer** at MSKCC as both a patient and volunteer, I am continually struck by the small acts of kindness and thoughtfulness around the entire institution.

Whether it is the amazing concierges at 53rd Street who meet and greet you by name upon arrival, or the security guards posted at all of the buildings, you feel like they remember you each visit. There are the people in Building Facilities who keep the buildings squeaky clean and continually restock the graham crackers and keep the hot chocolate flowing in the clinics. The MSKCC cafeteria is top-notch and has been recognized in the cuisine world because of that special effort. There are so many people to recognize, from lab technicians who remember which of your veins still work well to the session assistants who find the perfect slot for that scan your doctor requested. It would be hard to mention everyone in this small space.

Whether you are a cancer survivor or still in active treatment, it is important to acknowledge everyone who makes the experience at MSKCC so unique. **THANK YOU.**

Eileen F. Gould
Patient Editor

Where Are They Now? A glimpse at cancer survivors' lives post-treatment

Victoria Pfister Brown

Diagnosed with medulloblastoma in seventh grade when she was 12 years old, Victoria's scans have been clear for five years and she is now entering her sophomore year at the Rose Hill campus of Fordham University. While studying and enjoying life at Fordham with her fellow Rams, Victoria continues to raise funds for Memorial Sloan-Kettering through swim-a-thons, letter campaigns, and selling friendship bracelets. She lifeguards and teaches tennis during the summer; during the school year, she participates in intramural soccer and plays basketball and tennis with her friends. Victoria thanks her medical team of doctors and nurses for saving her life, because with their guiding hands she is able to lead a healthy, cancer-free life.

Carpe Diem

By Gina Costa-Goldfarb

Gina is the recipient of a bachelor's degree in psychology from CUNY Staten Island and an associate's degree in paralegal studies from St. John's University, as well as a graduate of the NYU School of Continuing Education in law and taxation. She has been a paralegal with a boutique law firm in lower Manhattan focusing on real estate law since 1986, and enjoys writing and participating in fundraisers for women's cancers.

My breast cancer diagnosis changed my life…all for the better!

I was diagnosed in July of 2012 with stage I invasive lobular breast cancer. I knew I was in the right place when I came to Memorial Sloan-Kettering for further assessment. If it weren't for the perseverance and expertise of all of the doctors at MSKCC, I don't know where I would be today. My initial feeling on diagnosis was shock and awe, but when my team of doctors told me where I stood, I felt I could positively move forward. Ultimately I underwent a double mastectomy and reconstruction surgeries.

My doctors were hands-on with me. I was able to cry with my breast surgeon. She understood me. My plastic surgeon and his nursing staff held my hand throughout the process and ultimately provided me with a sense of well-being and good feelings about myself and my body again.

My husband was amazing. He was my No. 1 cheerleader and caretaker. My children, ages eight and 11, were informed of my situation in terms they could understand and handled the situation like champs. I am a proud mother.

Prior to my surgery, I built a wall of support of friends and family around myself and my children so that I could withstand anything in my path. During and after the period of "forced rest," I had the time to rethink the way I was living. I was able to reassess my life. Before my diagnosis I was under a lot of stress for one person and doing more than I needed to, but that was my choice. Post diagnosis, I realized with eyes wide open that life had lots to offer. I became calmer and made adjustments to lead a healthier life. This was my second chance. I am still very high energy and determined, but now I try enjoying life in the moment. I can let certain things that are beyond my control "go" and realize that "tomorrow is another day." I wouldn't change any bit of how the last year of my life played out. It has helped me grow and placed me in a new sense of being.

I have been a real estate paralegal for over 25 years, but I am now seeking something more fulfilling. I started participating in an event called the EIF Revlon Run/Walk for Women in 2001 due to the loss of my mother to ovarian cancer, then to honor my sister, and now for me. I want to commit myself to the cause for the sake of my daughter, my future, and all women who have been or may be affected by this insidious disease.

This last year as a survivor has caused something to shift in me. I have always loved helping others and I believe that I have the ability to help other survivors in their journey as a result of my life experience and dedication to the cause. My diagnosis and journey have deeply affected me and in some ways I feel happier and healthier than I ever have. I recently enrolled in the Life Coach Training Program so that I can pursue my passion for helping others.

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phlebotomist, especially at the Breast Center, is excellent. We usually have one minute for words of wisdom or a good laugh. My social worker is there for me, along with the woman in Financial Assistance. The caring oral surgeon keeps me smiling through my dental issues. The Urgent Care staff couldn't be nicer.

And there are the behind-the-scenes people: technicians, janitorial staff, garage attendants, chefs, servers, volunteers, and the gift shop workers. This insidious disease, Cancer, has brought us together. Everyone who works, volunteers, or donates to Memorial Sloan-Kettering positively impacts patients' individual journeys to healing. You are priceless and I keep you in my prayers. Thank you for giving me and my cancer brothers and sisters the best care in the world, for treating us like family.

Ask the Survivor: Overcoming Late Effects of Cancer Treatment

By Kristin Oberle

Kristin turns 39 in December 2013. She is a biology teacher in an upstate New York high school.

Q ***How have you overcome late effects of cancer treatment to succeed in the workplace?***

A On Martin Luther King Day in 1987, I was enjoying my day off from school like any normal sixth grader. We received a phone call that changed my life forever. The MRI I had the week before showed a mass in my cerebellum. A biopsy at New York-Presbyterian Hospital/Weill Cornell Medical Center revealed that it was a benign astrocytoma growing slowly into my brainstem. With radiation being the safest way to stop the growth, MSKCC came into the picture, and I received two treatments of radiation a day for seven weeks. And that was that. Other than routine follow-ups, my brief adventure as an outpatient at MSKCC ended. I could move on to the summer and to my last year in middle school as a big seventh grader.

Schoolwork came naturally to me, so I continued to put my energy into what I was good at. My writing was impaired due to poor motor coordination associated with the tumor, but I was always given extra time to finish exams or papers. It was all worth it, because in high school I ended up with the top GPA in my class of about 150 students. It was such a special occasion that my doctor and nurse practitioner came to my graduation to hear my valedictory speech. I went to Duke University that August to study primate behavior in the biological anthropology and anatomy program.

One of the most difficult aspects of freshman year at Duke is that no matter how hard you try, you can consider yourself lucky if you squeak out a B- on a paper or test. Coming from a place where I expected straight As across the board, it was a rough welcome to Duke. Slowly and persistently, dedicated the time needed, and when I got to senior year, those As came! But when my immediate future as a primatologist pointed toward more schooling and more studying, I decided it was time to try something new. My primate research had taken on an educational aspect, so that seemed promising. I looked for jobs in environmental education, and began working at the Outdoor Education Center in Texas, a magnet program for fifth graders in the Houston Independent School District (HISD). After three years as an outdoors teacher, I got my certification in biology through HISD and stepped into the world of being a classroom teacher.

Back in New York 14 years later, I am completing my tenth year as a biology teacher in an upstate New York high school. Without a doubt, they have been the toughest ten years of my life. They have also involved the most growth. My students are in an inner-city school district, where gangs and drugs rule the streets of an economically depressed community. Education is not a priority for some of my students; but it is for others, and my classes consist of both types. In general, it is a huge challenge to find engaging strategies to help my students understand why the subjects they are learning are relevant to their sometimes violent world. Ironically, it was not until I stepped into this world that I have been able to understand my medical disabilities more fully.

I have always had a loud voice. I'm a singer, so the way I speak is fabulous for the vocal world. I never noticed that I was excessively loud. Most people at Duke just thought that I was a loud New Yorker. Friends in Texas thought I should get my hearing checked out; but it never lead to hearing aids until 2005, when I had my first experience with sudden hearing loss. The loss occurred in my right ear, and may not have been so scary had I realized that the hearing loss in my left ear was severe, probably due to radiation damage. I began wearing hearing aids, but still, with classroom acoustics, students who aren't the clearest speakers, and background noise, hearing students is not easy. I slowly started to realize that my ability to hear, and my students' perceptions of that ability, was

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Ask the Professional:
Cardiac Late Effects of Cancer Therapy

By Joanne Candela, ANP

Joanne is a nurse practitioner in the Adult Long-Term Follow-Up Program seeing adult patients who were treated for cancer as children or young adults. Joanne wishes to thank Dr. Wendy Schaffer, cardiologist, for her review of this article.

Q **Who is at risk for heart problems caused by cancer treatment?**

A Fortunately, most cancer survivors do not develop heart problems as a result of their cancer treatment. However, individuals who were treated with certain chemotherapies or radiation to the heart may be at risk for developing heart problems.

Q **What kind of heart problems can be caused by cancer treatment?**

A Heart problems caused by cancer treatment can include valvular disease, heart failure, coronary artery disease (plaque in the coronary arteries), heart attacks, and arrhythmias (problems with the rhythm of the heart).

Valvular Disease

The valves of the heart may be damaged if the heart was exposed to radiation during cancer treatment. About 5 percent of cancer survivors exposed to radiation affecting the heart will have long-term problems with their valves, and some will require surgery. Valves are like doors that prevent blood from flowing backward from one chamber of the heart to another. Valvular disease can be seen using an echocardiogram (ultrasound of the heart).

Heart Failure

A class of chemotherapy called anthracyclines can cause the heart muscle to become weak, leading to heart failure. Types of anthracyclines include: doxorubicin (also called Adriamycin) daunorubicin, epirubicin, idarubicin, and mitoxantrone. The higher the dose of anthracyclines, the higher the risk of heart failure. The risk of weakening of the heart muscle is usually less than 5 percent, and it may not develop until ten to 20 years after treatment. Children who were treated with high-dose anthracyclines should have their heart function tested for the rest of their lives. Survivors should also be monitored carefully during pregnancy, which can make a heart problem worse. The risk of heart failure from chemotherapy is higher for people who have also had radiation to the chest, or have other heart problems such as uncontrolled high blood pressure.

Coronary Artery Disease and Heart Attacks

Radiation to the heart can cause coronary artery disease and heart attacks. Some chemotherapy treatments may also increase the risk of coronary artery disease. Some survivors may benefit from early preventive measures to avoid heart attacks like taking aspirin and/or medications to lower their cholesterol. Please ask your healthcare provider before taking any medications.

Cardiac screening tests for blocked coronary arteries and preventive measures should be discussed with a cardiologist or another health-care provider who understands the special risks of cancer survivors. Even though cancer treatments can increase the risk of coronary artery disease and heart attacks, it is possible to decrease the risk by modifying other risk factors including smoking, obesity, high cholesterol, diabetes, and inactivity.

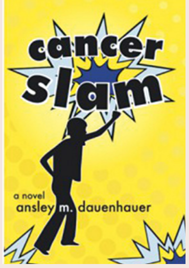
Arrhythmias

Rarely, radiation treatment and/or a class of chemotherapy called anthracyclines can cause arrhythmias (problems with the rhythm of the heart). An important one that may develop in people who were treated with anthracycline chemotherapy is called "prolonged QT." People with prolonged QT must avoid certain medications. Like other problems with heart rhythm, prolonged QT can be detected using an electrocardiogram (EKG).

Q **What advice do you have for cancer survivors with respect to heart health?**

A Cancer survivors can help themselves by knowing the cancer treatment(s) they received and talking with their health-care providers about it. Early detection and treatment of heart problems in cancer survivors can lead to long-term heart-healthy lives.

Resource Review: Cancer Slam By Barbara Golby, LCSW



A novel by
Ansley M. Dauenhauer

What is a school-age girl to do when she is expected to participate in a group report at school on the same day her mother is having surgery for breast cancer? Life as a pre-teen is hard enough without the added complication of having a parent with cancer. In *Cancer Slam*, Ansley M. Dauenhauer's novel for middle-grade readers, we get to know school-age Hannah and see how she navigates through rocky waters at home and in school after learning her mother has breast cancer.

We stand in Hannah's shoes as she gradually takes in the reality of her mother's serious illness. We observe as she struggles with worrying about missing Halloween and Christmas while at the same time wondering whether her mother will die. We watch how the initial excitement of having her grandparents visit while her mom is in the hospital quickly turns into a longing for her mother and a regular routine. And we can feel her uneasiness upon seeing her mother after surgery, looking so fragile and vulnerable.

In one particularly moving chapter, Hannah and her little brother are given the job of cutting their mother's hair before it begins to fall out. The children look forward to the event with excitement. However, as the time draws closer Hannah and her mother realize it is a lot more complicated than either expected. Hannah's reaction turns into sadness as she becomes aware of how hard this experience really is for her mother. At the same time she cannot help but feel hurt when her own wishes go unmet.

This story portrays a realistic cancer experience. People get angry and fight. Parents make mistakes. Children struggle with and solve difficult problems on their own. *Cancer Slam* offers a vivid portrayal of how a family can include children in a parent's cancer experience in a way that children can feel supported and learn to grow through one of life's most difficult challenges.

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one of the biggest issues negatively impacting the environment in my classroom. I have been very honest with students about it, since there is no way I can hide the fact that sometimes I just cannot hear what they are saying, even if I am standing right in front of them. Many students are cooperative, but empathy is tough to come by with my audience. I must consistently and effectively diffuse negativity and hostilities that arise from students convinced that I am ignoring them or just "playing dumb."

My impaired hearing is half the battle. Once I began pursuing teaching certification in Texas, I needed documented evidence to ask for writing accommodations when taking the state exams. I was a little shocked when testing showed a "delayed recall," which I now understand to be more of an issue with auditory processing. Funny…delayed recall – neurological damage from the tumor and radiation? I hadn't thought about it that way before. I've just always had to work harder to be successful; and as a student, I made the time to do the best I could. However, when you are in front of 26 high school students, it's a different story. Not only is it difficult for me acoustically to hear the pitch of certain voices in my classroom, but also when I need to ask students to repeat themselves, my brain can't quickly comprehend. I can never present myself as intelligently as I would like, and it is extremely frustrating.

Despite these challenges, this year I had some of my best experiences as a teacher. To break the cycle of negativity that quickly fuels up among some students in my classroom, I fostered student allies through encouragement. I have learned that I need to channel the natural "New Yorker loudness" in me into a passion for biology and what I am teaching, toning it down when discipline issues interrupt my enthusiasm. My greatest success was establishing SUNY Albany's Science Research in the High School program with two dedicated sophomore students who were willing to work with me. Our first-ever Science Research Symposium was a phenomenal success, and we are starting next year's Science Research in the High School course with more than 25 students! This was an incredible boost for me. The time and effort I spent this year to get the science research program off the ground was enormous, but well

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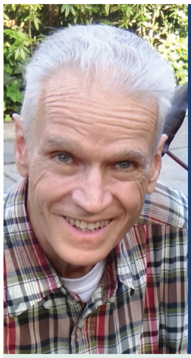

The Gift of Life — A Delicate Balance

By Carlo Schweizer

As candidate for a heart transplant in 2005, Carlo was diagnosed with prostate cancer. He received radiation treatments and a new heart the following year. Margaret, his dear spouse, is the essential supporter who keeps his hopes up during trying times.

We each make up a microscopic part in the mosaic of our incredible "living planet." As individuals, most of us take nature's complex balance for granted! It's ingrained in our brains that should illness strike, we can beat the odds and remain in control of our destiny!

My own thinking used to fit that pattern. But the past decade altered my outlook completely. I was confronted with the biggest lessons of my life.

Twelve years ago I was diagnosed with heart failure and faced a dire prognosis. And now I have just entered my seventh year of living with a transplanted heart, a beneficiary of phenomenal medical science! There still are no adequate words to express the miracle and elation that such a gift of life can entail. Though difficult at times, the special feeling of being a survivor stays with me.

An organ transplant necessitates immune-suppressant drugs, and living with a compromised immune system affects the body's delicate balance. Like the global environment, our immune systems are extremely complex. Even moderate changes can greatly affect a body's equilibrium over time. While waiting for a new heart I was diagnosed with prostate cancer and underwent radiation. Three years later my cancer suddenly recurred, necessitating new treatments. Belated radiation effects started to impact my body as well. A CT scan revealed one-sided hydronephrosis and doctors concluded that one kidney no longer drained adequately, likely due to tissue damage from radiation.

I am convinced that many factors have affected my well-being. Every treatment yields positive and negative reactions. I will never know what triggered my heart to contract a virus in the first place. Did the heart medications have anything to do with the ensuing prostate cancer? Finally, did radiation initiate the tissue damage that forced one kidney to shut down? While all these thoughts have crossed my mind, they remain immaterial.

Initially, heart medications kept me alive and radiation put my cancer into remission. After the phenomenal surgery, immune suppressants keep my transplanted heart healthy; but all these lifesaving measures also caused side effects. Science has developed phenomenal treatments that extend lives and greatly benefit mankind. Almost every day, we learn of newer and better methods to treat illness. I remain most grateful to have met outstanding physicians at the crucial times!

I visualize similarities between my illnesses and the global warming phenomena, which affects us all but is not fully understood. The advances that caused global warming greatly benefited economies and enabled wonderful inventions, though long-term "side effects" on our planet appear dire!

An intriguing "assignment" for our brightest scientists: Innovations remain the driving force to economies. They improve global living standards and well-being. If these scientists can come up with more novel ideas about how to better preserve and maintain nature's delicate balance at the same time, then the future for all of us, and for the planet, looks absolutely bright.

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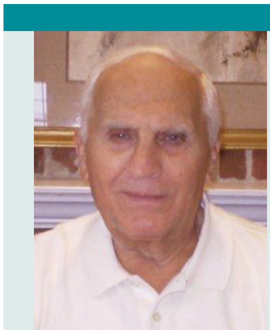
worth it. I felt like re-introducing myself to my administration, saying, "Hello, my name is Kristin Oberle. And this is what I can do to help you make this school and our students the best that they can be." To inspire kids, especially those who come to school with little inspiration in their lives beyond the streets, is a necessity. As with anything, there are good days and bad days: The good ones are becoming more frequent. After the ten toughest years of my life, I am beginning to echo the Peace Corps motto: Teaching is "the toughest job I'll ever love."



My Unwelcome Friend

By Richard A. Diem

For the past 11 years Richard has been a caregiver for men with Alzheimer's disease and a Eucharistic minister to the homebound. It lightens his cross to help others carry theirs.

Is this how I've come to think of you? Oh chronic pain of mine,
who still comes and goes in your own whimsical way just as you always
have since you first appeared over forty years ago.
Have I grown so accustomed to your insidious, malicious nature
that I can now rest assured you will leave in time after you have
tortured me with all the tools of your trade.
Because you selected the center of my chest as your staging area,
you have managed to scare me enough times so that I was taken
to a Hospital emergency room more than once.
You defied them, they couldn't identify you.
And through the years this is how it's been with many good
Doctors as even with your nomadic wanderings all through
my chest, they still can't find you.

Have I grown so accustomed to the fears that your mean spirited
intrusions give me that my heart can breathe a sigh of relief
when the pain releases me from this torture. And then I can say,
"Thank you," as one would to a friend because life goes on.

But you do over stay your visit, sometimes lingering for weeks
and then you're gone again, for as long as a month at times.
I thank God for this. I've prayed to be rid of you, I've prayed to
get along with you. "Love your enemies," the bible tells us, but
calling you an unwelcome friend is the best I can do.

One morning about twelve years ago, while I was at work you
burrowed your way deep into my chest with such excruciating
pain that I had to leave my job for that day. You became every thought
on the edge of panic. Why me? I thought. I went home and then trying
to divert my attention from your grip I wrote a poem about my pain.
Shortly after, in a moment of enlightenment, I realized this isn't just me.
There are a great many who suffer with pain and the poem became more
like a prayer for chronic pain sufferers. I called Monsignor Tom Hartman
who had a television show called, "Father Tom and faith." I read it to him
and he asked me to send it to him. From this he produced a show for all chronic
pain sufferers, reading my poem at the beginning and end of the broadcast.
You might say, unwelcome friend, that you served a good purpose that day.

And so I discovered that when you can turn why me into why not me, the
road to spiritual growth can be found.
From this began a deeper understanding with compassion in my heart for
the suffering of others. And, in fact, my unwelcome friend, you have become
a daily offering in my prayers that in some mysterious way God may use you to
alleviate the pain of others. In this way, suffering has found a meaning.

Memorial Sloan-Kettering
Cancer Center

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Resources for Life After Cancer (RLAC)

RLAC welcomes survivors to participate in programs that encourage healing through education and support.

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 Jennifer Wang at
patient2patient@mskcc.org.

Connections

is an online community for patients and caregivers. It provides a venue for conversations, support, questions, and companionship.

To register, visit:
www.mskcc.org/connections.

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.