

Bridges

Connecting Cancer Survivors



Bonjour from Paris!

By Ann Pfister-Brown

Just after visiting the Musée d'Orsay, we collapse at an outdoor café on the Left Bank. As I look over the table and listen to my daughter, Victoria, talk about her study-abroad experience, the sun is setting behind her and the light is bouncing off the buildings with radiant gleam. What an amazing city! I pause and reflect on where we found ourselves seven years ago while she continues to passionately describe her five weeks on her own.

Tori was 12 years of age when she was diagnosed with medulloblastoma, a pediatric brain cancer. Her MRIs have been clean for six years. Honestly, however, cancer manages to permanently etch memories that cannot be erased. I recall the journey in detail even though Tori has reached several milestones. Sitting in this café and thinking of her tenacity through adversity, I am struck by how raw it still feels. How the clumps of hair that decided to fall out on Mother's Day weekend haunt me. How the door to the radiation chamber locked shut while she bravely lay still on her stomach, alone, and how Sonja, our technician, was so kind. How we followed protocol and then eliminated one of the chemo drugs because her gait began to flop — wouldn't eliminating this drug compromise the outcome? The hearing loss. The fatigue. How I wheeled her in a wheelchair on Fifth Avenue waiting for her counts to improve.

■ Continued on page 8



Ann Pfister-Brown is a school counselor at St. Rose High School in Belmar, New Jersey. She earned a bachelor's degree in psychology from Trinity College in Hartford, Connecticut, and

a master's degree in counselor education from Kean College of New Jersey. She is also a National Certified Counselor. Although she has a background in dealing with crises, journeying through her daughter's diagnosis and treatment was challenging. With the help and understanding of an amazing medical team, colleagues, community, and family and a strong foundation of faith, she is able to share this story of her daughter's resilience and strength.

Interested in sharing your story?
Please visit www.mskcc.org/bridges

In This Issue

- 2 Editorial and Where Are They Now?
- 3 My Pain Finally Has a Name: Radiation Fibrosis
- 4 Ask the Survivor
- 5 Ask the Professional
- 6 Customized Search Engine for Patients & Caregivers
- 7 A Night at the Hospital



Memorial Sloan Kettering
Cancer Center



Editorial

By Eileen F. Gould

The world of cancer operates 365 days a year, 24 hours a day. It is a world that never sleeps, especially at Memorial Sloan Kettering. The holiday season, though, is a good time to reflect on the past year and to give thanks and recognition to those who have helped us.

When we consider a patient's support team during and after treatment, the medical profes-

sionals are often the first members who come to mind. Their roles are no doubt invaluable, but other important members of this team who deserve recognition are the caregivers. A caregiver can be a family member, friend, or anyone else who is close to the patient who provides help, support, and protection during an illness. Caregivers devote a tremendous amount of time, energy, and strength during the difficult time of a cancer diagnosis and treatment, and it can be exhausting, emotionally draining, and oftentimes confusing or overwhelming. Having been both a patient and a caregiver myself, I can honestly say that both roles are equally challenging. MSK understands that caregivers experience unique challenges and offers support services for them that are designed to address their specific needs. For more informa-

tion, please visit www.mskcc.org/cancer-care/counseling-support/caregivers-families.

We would like to offer a special thank-you to all the caregivers, whether you are a spouse, parent, family member, or friend. Your help and efforts can sometimes be overshadowed by the chaos of cancer, but your tireless efforts and comforting words are beyond appreciated.

The original mission of *Bridges* was to connect cancer survivors with each other and to share their stories of hope and survival, but we also welcome stories from MSK survivors and their caregivers. No experience is required in order to submit your story for *Bridges*. If you are interested in sharing with us, we encourage you to send your story to bridges@mskcc.org.

Where Are They Now? A Glimpse at Cancer Survivors' Lives Post Treatment

Dan Barry

Dan Barry was the City Hall bureau chief for *The New York Times* when he was diagnosed with a tumor in his trachea in 1999. An intensive chemotherapy regimen at Memorial Sloan Kettering eradicated the tumor, but cancer returned nearly five years later, in his esophagus. After more chemotherapy, he underwent an esophagectomy in January 2005. Nearly a decade later, Dan is cancer free, the father of two daughters, still writing for the *Times*, and very, very grateful to the doctors and staff at MSK.



My Pain Finally Has a Name: Radiation Fibrosis

By Teresa Levitch

“When we are no longer able to change a situation, we are challenged to change ourselves.” —Viktor E. Frankl, Man’s Search for Meaning

At 60 years old, I have been treated for and survived both Hodgkin’s lymphoma and breast cancer. With the support of family, friends, and the MSK team, I have lived and loved for an additional 20 years after my initial diagnosis. I am forever grateful.



After my treatment for Hodgkin’s lymphoma at Memorial Sloan Kettering in 1995, I thought I would simply return to my old life. Gradually, though, I began to notice new, vague symptoms. I couldn’t blow-dry my hair without my arms getting tired. My head seemed too heavy for my neck, causing a bobble-head motion. My upper back always ached — not a piercing pain, but something more insidious. I knew something was wrong, but also knew my oncologist would not be the one to address my problem. I was cancer free and released from her care, so my appointments were now once a year. I faced the same dilemma many cancer survivors experience. As my new pain caused more limitations in my daily life, it became clear I needed care, but to whom should I turn?

I began with my family physician, but he could find nothing wrong. He recommended a specialist that treated Lyme disease, but those test results were negative. I was then referred to a rheumatologist, but all tests were negative. In fact, she was at a total loss, as was each physician

previously. Every doctor raised an eyebrow and gave me a sideways glance each time they announced the test results were normal. I doubted myself and felt very alone in my pain.

I began to realize that my circumstances were not going to change, so I searched for a way to change my perspective. Pain and limitations had become a part of my daily life, and I embarked on a way to embrace this new life after cancer. This search led me to meditation and formally becoming a Buddhist, with a small personal ceremony with Lama Norhla Rinpoche, a Tibetan meditation master. Meditation helped me come to terms with my pain. Then, after finding the MSK Survivorship Program and becoming a patient of their Sillerman Center for Rehabilitation, I learned my pain had a name: radiation fibrosis. Both of these events changed my perception of pain.

There is no cure for radiation fibrosis, only management. Giving my pain a name changed the context

and made it real from a medical standpoint — and meditation transformed it, enabling me to accept these new limitations.

MSK is working to develop the medical narrative that describes what survivors may face after treatment. With 14 million cancer survivors, many suffering from issues like radiation fibrosis and other late effects of cancer and its treatment, it is imperative that the research of rehabilitation continues.

While I do not advocate that everyone become a Buddhist, mindfulness meditation may help transform the emotional toll any survivor may experience. I came to understand that I could not change my circumstance; radiation fibrosis is a real result of my treatment for Hodgkin’s lymphoma. However, I could change my perception of pain through meditation. Now, radiation fibrosis has become an affirmation that I am a survivor, changing my personal narrative — my story of cancer.

Ask the Survivor

By Ivy Brown

Originally from Queens, Ivy and her family moved in 1974 to London, where she spent her teenage years and was first diagnosed with Hodgkin's lymphoma. She returned to New York City in the early '80s and has since worked in the fashion and art industries. Now living in the Meatpacking District with her husband and two dogs, Ivy currently runs an art gallery and curates exhibits in the city.



Photo Credit: Kimberly Wang

Can you tell us about your experiences with cancer and dealing with the post-treatment effects?

In 1974, when I first was diagnosed with Hodgkin's disease — now called Hodgkin's lymphoma — I was 12 years old and my family had just moved to London from New York City. Before I'd even settled into my new life, I found myself in a hospital having my spleen and appendix removed, my ovaries “turned over” (the doctors thought it would keep them safe from the upcoming radiation), various lymph nodes removed, and a hole drilled in my hip bone to check the marrow. And then there were the blood transfusions. This was the beginning of a lifetime journey of keeping body and soul together.

All these many years later, I carry the effects of the journey etched visibly on my person. If I had to describe my posture, I would say it is turtle-like: My head is craned a bit forward, my upper back sloped in a manner that makes me resemble a human reptile. Besides not being an attractive look, it is literally a pain in the neck. I used to think I was lazy as I struggled

to carry myself upright. When I finally met other people who have undergone treatments similar to mine, I was so relieved to learn my posture was not by choice but by circumstance.

Do you use tools or devices such as a brace or a special sleeping pillow to help you deal with the pain, weakness, and frailty caused by your radiation treatments?

I use a brace that is still in the development stage. It's not pretty and I only use it when I am at home. I also do neck exercises about five days a week. I am constantly on the hunt for new pillows. It's a nightly struggle to find a comfortable sleeping position; last summer alone I tried three new pillows. No luck yet, but I am determined to find the right one eventually. Sometimes I just cannot get comfortable and I have to get up in the wee hours of the night and walk around before lying back down. My weak neck is compounded by the fact that I am prone to headaches. I go to a headache clinic, and it's been a wonderful alternative to using medication. I am a big fan of ibuprofen and lidocaine gel — I

would take a bath in the stuff if the tube had enough gel in it.

Have you found any treatments or exercises that have improved your function and quality of life?

Over the past 25 years I have done yoga and meditation, admittedly sometimes more regularly than others. After my double mastectomy, a plural effusion, and then an aortic valve replacement, it took a few years before I wanted to lie on my chest and stretch it. During the times when yoga was too physical, meditation was a better practice for me.

Recently I have been able to get back to a more regular yoga practice. It has been humbling. I am not able to do things I used to do. As my body continues to weaken, I change my practice to accommodate it. Lately, I have been working on strengthening my stomach muscles to help compensate for my weakening back. I try very hard to take what works and leave the rest at the door. Each of us needs to find our own tools to help offset the long-term side effects we experience. In addition, I have a universal humanistic spirituality

■ *Continued on page 8*

Ask the Professional:

Radiation Fibrosis Syndrome

By Michael D. Stubblefield, MD



Radiation therapy (RT) is an important part of treatment for many types of cancer. We use RT to cure cancers, including those of the breast or head and neck, or to decrease pain, improve function, and enhance quality of life, such as with metastatic tumors of the spine. The basic idea behind RT is to kill fast-growing radiation-sensitive tumor cells while sparing the relatively insensitive and slower growing normal cells of the body. Unfortunately, normal tissue is not completely immune to the effects of radiation.

Radiation fibrosis, or RF, is the abnormal accumulation of protein and other changes that occur in radiated tissues. RF is an “immortalized” process, which means it can continue to progress forever due to complicated biologic feedback loops that have malfunctioned. Radiation fibrosis syndrome (RFS) is used to describe the problems that patients experience as a result of RF. RF can affect any tissue in the body including nerve, muscle, lymphatic, and bone tissue; tendons; ligaments; blood vessels; and more. An important point to understand about RF and RFS

is that only the tissues in the radiation field are affected directly. It’s also important to understand that structures such as blood vessels, nerves, and lymphatic channels that pass through an area of RF may cause issues away from the radiated area. For instance, a patient who was treated for breast cancer many years ago using old radiation techniques may have RF of the chest wall and armpit that affects the nerves, blood vessels, and lymphatic channels of her arm. As a result of this, she may have RFS that includes lymphedema (arm swelling), brachial plexopathy (nerve pain and weakness in the arm), clotted blood vessels, or other issues.

Survivors commonly affected by RFS include those treated for Hodgkin’s lymphoma and head and neck cancers because of the high doses and large radiation fields used to cure them. Fortunately, our radiation treatments have improved dramatically, and RFS from standard treatment of diseases like breast and prostate cancer is relatively uncommon.

The treatment of RFS varies dramatically and depends on

the issues faced by individual patients. There is no cure for the biologic processes that underlie RF. Treatment depends on first identifying the specific disorders faced by patients using a comprehensive history and physical examination. Additional testing such as MRI and EMG (nerve and muscle testing) is often necessary to obtain specific information and clarify competing diagnoses. Treatment almost always involves specialized physical therapy techniques that stretch and massage muscles and organs and help with things like balance and movement. Occupational and lymphedema therapy are incorporated when necessary, and medications, particularly nerve stabilizers, are often used. Botox and trigger-point injections are very useful for some patients; bracing, splinting, and other techniques may also be necessary.

While there is no way to reverse the progressive fibrosis that underlies RFS, proper identification, evaluation, and treatment can improve the function and quality of life of survivors affected with this disorder.

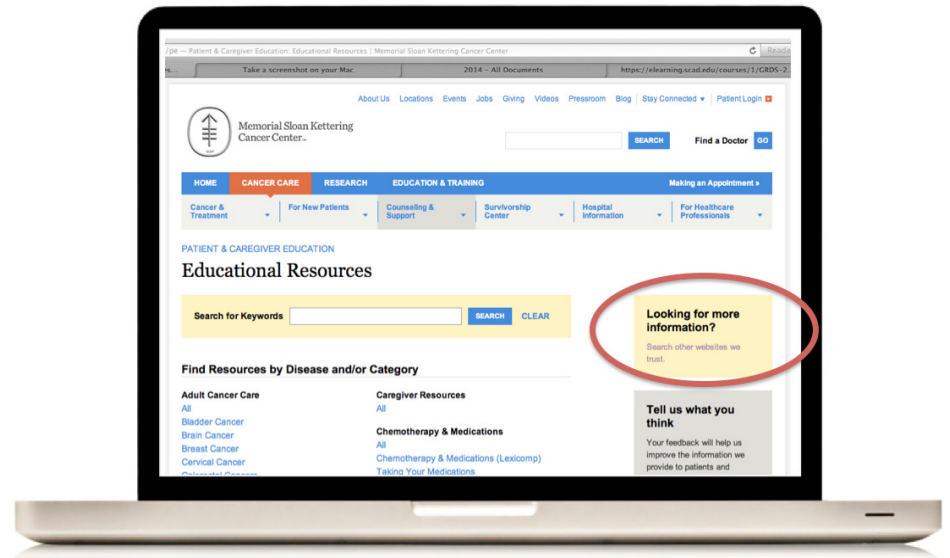
Customized Search Engine for Patients & Caregivers

By Chasity Walters, PhD, RN

The Internet can be a great resource when you want to learn about cancer. Millions of websites offer information about the full range of cancer prevention, treatment, and survivorship, but not all are equal. To ensure you're getting quality information, it's important to know where the information is coming from and how it's been reviewed. To take that burden away from our patients and caregivers, MSK provides vetted information all in one place.

MSK's Patient & Caregiver Education website offers access to nearly 10,000 educational resources, including both text and video. The website is open to the public, allowing anyone to search for resources developed and/or reviewed by our expert staff. MSK clinicians are able to prescribe these resources to patients by sending them directly to the patient portal, MyMSK. There, patients can access the most up-to-date resources anytime, search for additional resources, and access help from one of our librarians.

Sometimes that information isn't enough. You may want to know more about a particular cancer to make the decision that's best for you, or you may want to look to others for online support. To help you manage what can be an overwhelming amount of information, we've recently added a customized search that narrows



the Internet to only cancer-related websites that we trust. The sites listed in the search have been reviewed by MSK's expert staff, including clinicians, education specialists, and librarians, to be sure the information is high quality, unbiased, up-to-date, and intended for readers like you.

Of course the information that you find on a website does not replace talking with your healthcare providers. If you read something online that doesn't agree with what your healthcare provider has told you, ask him or her about it. Together you'll make the best possible decisions about your care.

To find this resource, please visit the MSK Patient & Caregiver Education page at www.mskcc.org/pe and click on "Looking for more information? Search websites we trust."

Rising Voices

is a fun and lively singing group just for patients and survivors. Open to all MSK patients, Rising Voices is a free, supportive activity sponsored by the Integrative Medicine Service.

To join, please contact Anjoli Mammen at mammena@mskcc.org or call 646-888-0800.

Resources for Life After Cancer (RLAC)

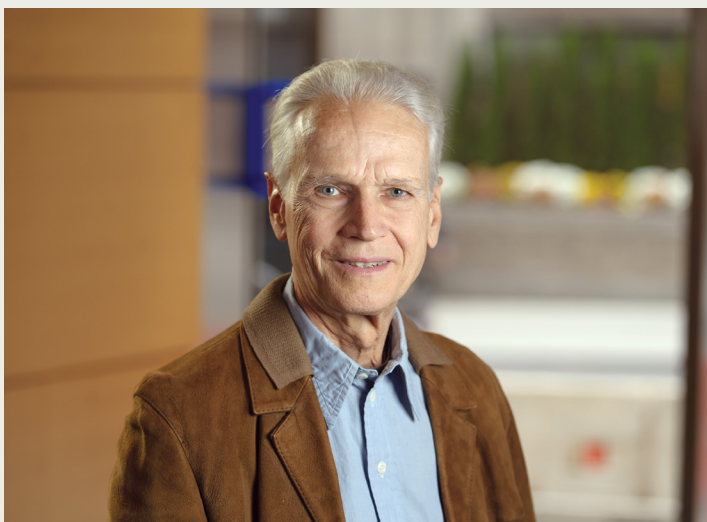
RLAC welcomes survivors to participate in programs that encourage healing through education and support.

Please see the online calendar at: www.mskcc.org/livingbeyondcancer.

Visible Ink™ A One-on-One Writing Program for MSK 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.



A Night at the Hospital

By Carlo Schweizer

A “short-term” business transfer 39 years ago brought me to New York. The city certainly changed my life. As the 1960s slogan goes: “You have to be crazy to live in New York, but it would be nuts to live anywhere else!” Now for me, it’s also the best place to receive cancer treatment.

Over the years, I became a frequent visitor to MSK and have spent many nights in their beds. On one particular visit, after spending an initial night in Urgent Care, I was assigned a room where I hoped to spend a quieter and less disruptive night.

I’ll admit that all my life I have been a light sleeper, and I especially dread hospital nights as they often turn into nightmares. My room neighbor was an old, frail man, and I anticipated he would not cause much disruption. I watched television until around 11:00 PM and then tried to find a comfortable position on my awkward “movable” hospital bed. This certainly was no easy task with all the tubing coming out of me! I was just about to fall asleep when my neighbor was due for his nebulizer treatment. After that interruption, I settled back down, the lights were out, and I was imagining lying on a sandy beach...when all of a sudden the lights were switched on again and it was time for my vitals. Then, approaching sleep once again, in the semi-dark room I suddenly noticed two people tiptoeing toward my bed. I tried to say something to them when the lights came on and the hospital assistant and her patient

realized that they had entered the wrong room. Without a single word or switching off the light, they turned around and left — I needed to holler!

I calmed myself down again and sleep must have just taken over when my neighbor called the nurses’ station because he needed help to go to the bathroom. When the help finally arrived, I surmised it was too late and more “action” was needed. After the racket was over, lights were turned off and calmness returned. About ten minutes must have gone by when I heard his rhythmic snoring; not even the beeping of IVs seemed to bother him.

I was upset, restless, and half asleep when a technician tapped my shoulder to draw my blood. I asked her the time and she said, “4 o’clock, I start at 3!” Why do vitals and bloods have to be taken in the middle of the night? I knew they would be coming for my vitals at 5:00 AM – and they sure did.

Could it be possible that I finally found some sleep toward the morning? The amount of sleep I got that night would be much better expressed in minutes rather than the

commonly used measure — hours. I did finally fall asleep again but was abruptly awoken by a doctor’s early visit as he was checking on my dear neighbor. It was 6:45 AM and daylight was breaking — and with it, signaling the end of another night at the hospital.

Anyone who has stayed the night at a hospital can tell you that it can be a frustrating experience. Overnight stays can be challenging for a number of reasons: We are usually at our sickest, it is a new and foreign environment and we are completely surrounded by constant activity and the associated noises and distractions. Nevertheless, hospitals are truly remarkable institutions where amazing and wonderful things happen and countless lives (including mine!) are saved every single day. New medical treatments make it possible to extend and improve the quality of life for millions while the kindhearted clinicians do what they can to comfort us. Staying in the hospital is oftentimes a necessary part of treatment, but it is back at home in our own beds, surrounded by comforting familiarity that we are able to heal.

■ *Continued from page 1*

“...and so you need to read my final exam essay on Paris and the World Wars.” I smile while my eyes water. I am so proud of Tori and all she has achieved in spite of her diagnosis. She is entering her junior year at Fordham University. Her conscientious ways aid her as she diligently strives to improve her GPA each semester. Occasionally, she becomes frustrated with how long it takes her to complete coursework, or how she must complete forms each semester to continue her accommodations of extended time for exams. These are extra steps that those who have not experienced cancer’s path need not contend with.

It is exhausting to witness her perseverance, but Tori will not relinquish her resolve. Her middle school science teacher once commented that Tori makes a teacher work hard. She does, but the expectation is that her success

then becomes each teacher’s or professor’s success. Tori wants to be successful. That feeling of accomplishment and finishing a race is at her core. As the time in Paris concludes, it seems fitting that we witness the final day of the Tour de France on the Champs-Élysées. Thousands of miles and numerous weeks through England and France and the cyclists zoom by with still-vibrant energy. Analogous to Tori’s race!

Thank you to all the miracle workers who have contributed to Tori’s life experiences since 2007. I have witnessed extraordinary patience and commitment from her Memorial Sloan Kettering medical team; her local physical therapist, who was dedicated in assisting her in regaining her strength; and her godfather, who guided us through a challenging time.

■ *Continued from page 4*

that has helped me through the hardest of times and added to the quality of my life.

I am not the kind of person who reads up on every potential side effect. I am a creative person, and to have all those possibilities looming in my head would be detrimental to my well-being and quality of life. My body tells me what I can and cannot do, and it speaks up pretty clearly. I just have to keep listening so I don’t hurt myself. Some of what I’m experiencing is the late effects of

treatment, but some of it is simply the natural aging process.

We cancer survivors have a bit more to deal with than most, though not as much as others. Everyone has issues; no one gets through life without living through complicated circumstances. I consider myself a very lucky person, a modern miracle of sorts, despite the difficulties I’ve endured.

And who knows, I may just outlive them all.

Patient Editor
Eileen F. Gould

Managing Editor
Katie Decker, MA

Advisory Committee
Annamma Abraham Kaba
Joanne Candela, ANP, MPH
Patrick Dooley
Diane Dunst
Jennifer Ford, PhD
Barbara Golby, LCSW
Ellen Greenfield
Judith Kelman
Kimarie Knowles, LCSW
Mario Lacouture, MD
Mary McCabe, RN, MA
David G. Pfister, MD
Rebecca Steed, NP
Michael Stubblefield, MD
Clare Thomas

Cover Bridge Photo
Duane Bailey-Castro

Design and Photography
Medical Graphics and Photography

Bridges is a publication of the
Cancer Survivorship Center at MSK.

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.

Patient and Caregiver Volunteer Program

The Patient and Caregiver Volunteer Program connects current patients and caregivers to volunteers who have experienced a similar diagnosis or circumstance related to cancer. If you are a former patient or caregiver of someone who has completed treatment, please consider becoming a Patient or Caregiver Volunteer.

For more information, contact
Maurisha Osi at 212-639-5007 or
patient2patient@mskcc.org.



Memorial Sloan Kettering
Cancer Center

If you would like an email
copy of *Bridges*, please sign
up at www.mskcc.org/bridges
to join the mailing list.