

Bridges

Connecting Cancer Survivors



A Lump in My Throat

By Sharon Berlan

My life was full and busy as a retail executive for a major department store. I traveled all over the world many times, enjoying my career and the friends I made. But one day, I felt a lump in my throat that would not go away. I swallowed, and it felt like something was stuck. After seeing various doctors, I had surgery to remove my adenoids.

But the lump in my throat persisted, and over the next year, I had increasing trouble breathing through my nose. I found another ear, nose, and throat specialist who correctly suspected a very rare disease, chordoma. It is a spinal tumor that can appear anywhere from skull to sacrum. It affects only 300 people a year in the United States, an incidence of one in a million. Lucky me! Why could I not win the lottery? From here on my life would be changed.

Over the course of the past few years, recurrences, side effects, and other issues have led to 17 surgeries and many different kinds of radiation. This is a chronic disease that has no cure. I have been stable recently and am grateful for that. There currently are no drugs for chordoma patients. This fact has led me to become very involved with research and helping other patients to get to the very few experienced doctors.

I help moderate a Facebook group that has grown to 1,000 members. It seems miraculous to have so many for support when we would ordinarily never have met anyone else with chordoma. Social media has made this possible and proven very helpful the world over. Our motto is “We are all in this together.” It makes me feel good to be

■ *Continued on page 7*



Sharon Berlan is a retired retail executive. She was diagnosed with chordoma in 2004 and has had various surgeries and treatments. She lives in Manhattan with her husband, Robinson, and their two cats, Serena and Angelica. Sharon enjoys walking around the city and experiencing all it has to offer.

In This Issue

Editorial and Where Are They Now?	2
Ask the Professional	3
Letter to a Fellow Patient	4
Ask the Survivor	5
Father Down the Road	6
Resource Review	7



Memorial Sloan Kettering
Cancer Center

Interested in sharing your story?

Please visit www.mskcc.org/bridges



Editorial

By Eileen F. Gould

The *Bridges* newsletter begins its tenth year of publication with this issue. We are just as excited to share your stories of hope, inspiration, and survival today as we were all those years ago.

Bridges has always been the result of considerable collaborative effort, and I, along with our Managing Editor Katie Decker, would like to take this opportunity to thank one group in particular, the *Bridges* Advisory Committee. These patients, caregivers, and professionals have generously dedicated their time and expertise to guide us in creating the wonderful newsletter that *Bridges* has become. Additionally, we want to thank several departing committee members for their many years of dedication to the newsletter: Jennifer Ford, a psychologist in the Counseling Center; Mario Lacouture, Director of the Oncodermatology Program; and David Pfister, Chief of the Head and Neck Oncology Service.

As a personal milestone, I've recently just reached 39 years as a cancer survivor. Like many of my fellow survivors, I have experienced some bumps in the road along the way. Nevertheless, I am still here almost 40 years later, grateful to still be traveling through the world of cancer survivorship.

Where Are They Now?

After four years of clean scans, I dared to hope I would remain cancer-free. Unfortunately, new tumors appeared, but now more than ten years after my initial diagnosis, I continue to pursue my passion for painting. I have taken my paint box back indoors, intent on finishing a series of portraits of my grandchildren. I am immensely grateful that these years have allowed me to witness the birth of a new grandchild and other family milestones. In 2014, I celebrated my 50th wedding anniversary by taking my children and grandchildren to visit their father's birthplace in Israel.

I have also had the opportunity to develop unexpected interests. Solely to counteract the effects of chemo, I enrolled in a yoga class for bone strength. One year and 200 study hours later, I was certified to teach yoga. I am continuing my studies while I teach yoga for cardiac health at a local hospital and gentle yoga at a senior day care center. Last year I climbed to the top of Cape Horn in Chile to stand in Eagle pose.

From time to time, cancer interferes. However, I know that the doctors and entire staff of MSK are protecting me: They keep me strong and lift me up. Words are insufficient to express my gratitude.

– Sue Warshavsky



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 Wendy Bonilla at 212-639-5007 or patient2patient@mskcc.org.

ASK THE PROFESSIONAL

Bone Health and Nutrition

By Christina Stella, MS, RDN, CDN, CDE

What is osteoporosis, and how is it found?

Osteoporosis is the most common bone disease. It is characterized by thinning, weak bones that fracture more easily. The disease develops when more of the cells that break down bones are being made than the cells that form bones. A bone density test measures the health of your bones.

Why can cancer and cancer treatment potentially cause osteoporosis?

Both men and women who have had cancer are at an increased risk for developing osteoporosis. Cancer cells that start in or spread to the bones can weaken them. Also, certain chemotherapy drugs limit the production of estrogen and testosterone. These hormones are necessary to build strong bones and protect them from injury. Hormone treatments for prostate and breast cancer can weaken bones too. Radiation targeted at bones is toxic to them. Patients who take steroids as part of their treatment, especially for the long term, are at risk of developing osteoporosis because the cells that form bones are inhibited.

What kind of diet will help keep my bones strong?

Vitamin D and calcium are micronutrients that work together to build and maintain strong bones. The more calcium and vitamin D in your diet, the stronger your bones become.

The best way to get calcium is to consume foods high in the nutrient. Cow's milk and foods made from cow's milk usually have the highest amount of calcium per serving. Nondairy sources of calcium are soy, rice, and almond milk; canned sardines and salmon; cooked collard greens, kale, bok choy, and Brussels sprouts; white beans; tofu and edamame; almonds; and fortified cereals and juices. Look at the labels and choose foods with a high percentage of calcium. For example, a food with 30 percent calcium is a better choice than a food with 10 percent calcium.



Nutrition can fight the negative effects that cancer treatment can have on bone health. Registered dietitian Christina Stella, a nutrition and diabetes educator, weighs in on the importance of nutrition for strong, healthy bones.

Vitamin D is more difficult to find in food. Cod liver oil, canned salmon, fresh fatty fish like salmon and tuna, and fortified milk and orange juice are all great sources.

How much daily calcium and vitamin D do I need?

Men and women ages 19 to 50 need 1,000 milligrams of calcium. After age 50, women need 1,200 milligrams and men need 1,000 milligrams of calcium. The potency of vitamins is measured in international units (IU). Men and women up to age 70 need 600 IU of vitamin D. After age 70, they need 800 IU.

What do you recommend for calcium supplementation?

You can take both calcium and vitamin D as supplements if you can't get enough from food. Check with your doctor before taking either nutrient. The most common forms of calcium supplements

■ *Continued on page 7*



Letter to a Fellow Patient

By Lisa DiMaggio-D'Ottavio

Lisa is a friend, a mother, a daughter, a sister, and a survivor — as well as a wannabe writer. She is just so happy to still be here!

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.

Dear Fellow Patient,

You don't know me, but I felt compelled to write you this letter. Almost nine years ago, I was diagnosed with breast cancer. I found out in August 2006 that I had an aggressive form of HER2-positive ductal carcinoma. It had spread to my lymph nodes, which meant chemo and radiation — lots of it. That September, after three “second opinions,” I had my right breast removed and reconstruction performed the same day. I was 42. There was no history of aggressive breast cancer in my family. Go figure.

The flurry of activity that happened after my diagnosis was just that — a flurry. I worked full time throughout all of the treatments while raising my two children (who were 14 and 11 at the time) with my husband (who unfortunately was not a big help). I didn't do this to be a hero — I did it to survive. I needed to get up every morning with a purpose. I needed to get dressed and put on a brave face because I really didn't know how else to act. Of course, I was scared to death. My friends and family rallied around me, made meals for us, drove me to appointments, called me, sent emails and cards (which I still read), and created a website so people could keep up to date on my procedures.

I'm so glad that I let them in. I would not have made it without their support, but it was on my terms. I made sure to speak up when I didn't want to talk or see people.

Another “discovery” that I made was group therapy. It took me a few months to convince myself to go, but it was a decision that changed my life. I met people there with all different types of cancer. I could be my “sick self” there if I wanted to be. I was allowed to speak up or not, cry if I needed to, or just talk about what I was going through without feeling sorry for myself. I definitely had some “feeling sorry for myself” days too, but being around people who had also been inducted into the only club that no one wants to be in helped me cope with the unknown. I only regret that I didn't go as soon as I was diagnosed. It made that much of a difference for me.

I also discovered writing. A wonderful local writing professor/therapist-in training/hairdresser/gourmet chef volunteered her time at a writing class. I saw the sign-up sheet out of the corner of my eye when I was leaving a group session one night and thought, What the heck? And the rest was history. I remember being in the chemo chair with my headphones in, the music blasting, writing my assignment for the week, and transcending my nightmarish reality. Four of my stories have been published and performed as part of Memorial Sloan Kettering's Visible Ink program.

I gained so much confidence and felt as if something good came out of the worst time in my life. And honestly, now I measure everything by still just being here...nothing else really matters to me.

I wish you nothing but good things and positive thoughts. I don't have any more answers than I had nine years ago, but I can tell you that I live every day as best as I can. Have faith in the love that has brought you this far. If you ever need someone to talk to, I'm always here.

Peace and love,
Lisa

ASK THE SURVIVOR

Losing Weight After Cancer

By Shari Cherry

What prompted you to lose weight after being treated for breast cancer?

As I walked out of my oncologist's office, I asked her, "What can I do to prevent the cancer from coming back?" She replied, "Lose weight." At age 50, I was overweight, (well, if I'm being honest, closer to obese) and approaching menopause. My mind told me that losing weight would be impossible. After my radiation treatment ended, I began to reflect on the conditions inside my body that would allow breast cancer to grow. Being obese increased my risk of breast cancer, and if I stayed overweight, statistics showed that I would double my risk of a recurrence. Once free from the trance of self-neglect, I decided to change my eating habits and consume only foods that serve my body rather than hurt it.

How have you changed your eating habits since becoming a cancer survivor?

I found that my eating habits changed once I changed the way I thought about food. I forced myself to stop believing that I'd never lose weight or be healthy. Every time I started thinking it would be impossible to meet my health goals, I'd tell myself to drop the thought. This mind shift takes practice and consistency.

Now before I eat something I ask myself, "Will what I'm about to eat help me or hurt me?" This question helps me choose foods that nourish my body. I feel an inner sense of responsibility to my body now that I've vowed to use food to heal it. This empowering process is how I lost 70 pounds without dieting.

Stopping before I eat something and being very aware of the ramifications on my body are things I still do today even after reaching my health goals. There are days I choose less-healthy options, but since I am now making conscious choices, eating one or two cookies will not hurt my body as much as eating the whole box like I used to.



From her home in New Jersey, Shari Cherry, a wife and mother of three sons, writes on her blog about how cancer gave her superpowers. Through self-reflection, her powers of self-care, gratitude, and intuition continue to grow.

What are some tips you can you share?

Be accountable to yourself. I keep a food diary, which helps me stay committed. I also don't let others sabotage my nutrition goals. It doesn't matter what other people are eating. Just pause and remind yourself to choose foods that heal and serve your body. This practice is so empowering!

Learn about nutrition and weight loss. I've taken out library books, surfed the Internet for articles, and read health and fitness magazines to gather recipes and information on foods that fight cancer and other diseases. I've also learned to read food labels more carefully. And if possible, enlist the support of nutritionists, dietitians, and personal trainers.

■ Continued on page 7

Father Down the Road: Parenthood Provides Perspective on Childhood Cancer

By David A. Eisenberg



A longtime resident of New York, David A. Eisenberg now lives with his wife and three kids amid the interminable cornfields of central Illinois, where he teaches all things political science (and some things not) at Eureka College.

It was shortly after my illness had been given a name — something it had been wanting for almost a year — when my father and I found ourselves sitting silently in the waiting room. My mother, who had been at my side when the doctor pronounced that fateful word, found the news too much to bear, and beneath the weight of it, she was compelled to remain in the doctor's office a little while longer. As we awaited her return and further directives from the hospital where I was to be admitted for the night, I asked my father how he was doing. "Better than your mother, but" — and this he could not explain — "it seems not as well as you." I didn't have an explanation for my apparent impassivity. Today, 17 years on, I trust I could put one forward, though given the passage of time and the tendency to color past events in lights different from the ones in

which they initially appeared, I am not sure I could do so accurately.

But I can offer a different explanation — one that does not account for my composure in that moment but does explain why, immediately after I was diagnosed with cancer, neither my mother nor my father fared as well as me.

To suffer is difficult; to see your child suffer more difficult still.

If one sought to rationalize this, one might say that the parent suffers doubly, first as one who commiserates with his or her suffering child, and second as one who experiences the child's suffering as his or her own. For those who have not only given life but, moreover, given their

lives to their children, how could it be otherwise?

None of this was known to me at the time. It is only now that I have children of my own that I can begin to appreciate what my parents — as parents — must have gone through.

In the short time that our kids have strutted and fretted upon life's stage, they by and large have been paragons of good health. I am acutely aware of their, and hence our, good fortune. Still, illness and mishaps are inevitable parts of life. When they have befallen our boys, I have suffered disproportionately. A high fever that would cause me some discomfort were it my own causes me considerable distress when it afflicts one of my sons.

All this underscores the remark I once made to my wife, only half in jest, that I have no idea how my parents survived my cancer. But they did, of course, as did I. Their unsparing support was immediately evident. Only later, when I became a parent, did I learn to fathom their unfaltering fortitude.

In this regard, as in so many others, fatherhood has endued me with a deeper wisdom and greater sense of gratitude.

■ *Continued from page 1*

doing something to aid others with this very scary disease. One of the positive lessons I have learned is that this change in life has brought time to pursue things I enjoy. While I had a busy, intense career, I did not have the ability to indulge in new interests.

I had no room in my schedule for anything but work! Now I have become a bird-watcher, and I spend a lot of days outside, learning about nature and meeting new people. Central Park happens to be a haven for migrating birds so I have gotten to know it very well. And this also gets me exercising by walking a lot!

I live in New York City, very close to MSK. I discovered amazing programs available to patients. I have taken art classes, from watercolor to making jewelry, in the Art Expressions program. Watercolor has awakened a talent I enjoyed as a child but had forgotten about in the hubbub of adult life. Now I love painting and even sell some works for donations to nonprofits. I send cards that I have painted to patients and friends.

I am honored to be part of the Visible Ink program, which publishes patient work. This has also shown me that spending time on a new hobby can lead to wonderful joy. And amazing new friends! Overall, I feel grateful that I can utilize my time as I wish, enjoying life. I can honestly say there is a positive side to what my journey has been. I would not have thought so when diagnosed and my life was turned upside down. But in hindsight, I can say I am happy!



RESOURCE REVIEW

65+ Program

Older adults get cancer more often, and treating their disease can be very complex. Newer drugs, improved supportive care, and less-invasive surgical techniques have opened up the possibility of cancer treatments to even the oldest old. For these patients, cancer is often just one of many health problems. Older adults may have special needs and considerations. These might include a lot of medications, more risk of drug interactions, an increased financial burden for care, problems related to multiple healthcare providers, and caregiver stress.

■ *Continued on page 8*

■ *Continued from page 3*

are calcium carbonate and calcium citrate. Avoid taking more than 500 milligrams of calcium in supplement form. The body absorbs less calcium when a supplemental dosage is excessive. Also, research studies have found negative health consequences to supplementing a high dose of calcium. Your doctor can determine if you need a vitamin D supplement from a simple blood test.

Besides diet, what other steps can I take to keep my bones healthy?

Keep your bones strong by exercising regularly, especially with weight-bearing exercises. Limit your alcohol consumption and avoid smoking.

■ *Continued from page 5*

Exercise. I enjoy high-intensity interval training, which is a fast-paced workout in short bursts plus weight lifting. You don't have to lift heavy to feel strong and be invigorated!

Try new foods. I enjoy trying new foods that I read about, like when I read about the wonderful health benefits of sardines. I had never eaten sardines yet had strong negative thoughts about them. I persuaded myself to try them, and they were delish! Do sardines really taste good or has my intense newfound love for myself influenced my mind so I have ease and joy when eating to serve my body? Either way it doesn't matter, not since sardines taste way better than how breast cancer feels.



Chief of the Geriatrics Service at MSK, Beatriz Korc-Grodzicki leads the 65+ Program, which focuses on older people with cancer.

■ *Continued from page 7*

Memorial Sloan Kettering is committed to providing older people with cancer with the treatment and support they need. The 65+ Program in the Department of Medicine is dedicated to this goal. It brings together experts from various fields who have a special interest in the care of older adults with cancer. This group includes geriatricians, geriatric nurse practitioners, oncologists, nurses, social workers, pharmacists, counselors, and specialists in rehabilitation, nutrition, and supportive medicine. The 65+ team discusses new ideas and develops educational programs, quality initiatives, and research projects for older people with cancer. At the same time, members of the group also see MSK patients and survivors during cancer treatment and follow-up care.

The Geriatric Service was established as an extension of the 65+ team to help people with cancer who also have medical conditions that are common in older adults. The service provides individualized, patient-centered care. We identify frail patients who are at an increased risk of surgical complications or side effects from chemotherapy. We also try to increase awareness of geriatric issues, such as falls, memory loss, and functional dependency. A busy non-geriatric practitioner might not be on the lookout for those during routine cancer care. The service does research and provides departmental and national leadership in geriatric oncology.

Along with the Resources for Life After Cancer program, the 65+ team gives quarterly lectures to the public on subjects related to the care of older people with cancer and survivors, such as coping with cancer pain and dementia. Everyone is invited. For information on the lectures or to register, please email rlac@mskcc.org or call 646-888-8106. For information on the Geriatric Service, call 646-888-3659, or speak to your MSK doctor.



Memorial Sloan Kettering
Cancer Center

Patient Editor
Eileen F. Gould

Managing Editor
Katie Decker, MA

Advisory Committee
Shrujal Baxi, MD
Melanie Bilkis
Wendy Bonilla
Joanne Candela, ANP, MPH
Patrick Dooley
Stacie Corcoran, RN, MS
Diane Dunst
Barbara Golby, LCSW
Ellen Greenfield
Judith Kelman
Mary Ellen McEvily
Ann Pfister-Brown
Nirupa Raghunathan, MD
Larissa Regala
Clare Thomas

Cover Bridge Photo
Duane Bailey-Castro

Produced by the
Department of Communications

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

Memorial Sloan Kettering Blood Donor Program

Help MSK patients by donating blood or platelets to the MSK Blood Donor Program. Both general and directed donations are welcome. Please call for hours and more information.

MSK Blood Donor Room
Schwartz Building Lobby
1250 First Avenue
212-639-7648 or 212-639-8177

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.

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