

Bridges

Connecting Cancer Survivors



The Best Gifts Are Not Under the Tree

By *Stephen Reimann*

The lumps of coal for our stockings came early last year — December 17 to be exact.

The lumps, multiple pulmonary nodules, were identified by a routine CT scan. A little more than a year after major surgery and 18 weeks of chemo, the cancer had returned. We were told that a year without recurring disease was pretty good, statistically speaking. But it didn't do much to make the season bright.

After a brief respite in Florida was eight more weeks of traditional chemo, during which the nodules continued to grow. Not the hoped-for results, but at least no hair loss.

That brought us to another summer filled with uncertainty. The “gold standard” chemo regimen didn't work. What next? Surgery and ablation were ruled out. This brought us to the “science” part of the MSK marketing slogan “More Science. Less Fear.” The promising clinical trial of a protein inhibitor with a strong link to endometrial cancer did not pan out because of chemistry mismatches. Two equally promising clinical trials were ruled out because of diabetes complications. Then came DNA testing, which revealed a genetic predisposition to a new type of drug recently approved for endometrial cancer. Finally, a viable chance for success.

Or was it? Perhaps it was the only remaining option after the others did not fit? It didn't matter.

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Chris and Steve Reimann live in Centerport, New York. Prior to being diagnosed with stage IV endometrial cancer in the summer of 2013, Chris spent her professional career establishing national programs for vulnerable populations. This December, Chris and Steve will be spending their 50th Christmas together, with renewed appreciation for the gift of life.

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Memorial Sloan Kettering
Cancer Center

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Please visit www.mskcc.org/bridges



Editorial

By Eileen F. Gould

MSK recently held its annual Survivorship Celebrations at the Manhattan and regional locations. More than 500 survivors and their families and friends attended the Manhattan event.

Scott Hamilton, a cancer survivor and 1984 Olympic gold medal-winning figure skater, provided the keynote address in Manhattan along with two patient speakers who also shared their personal stories of survivorship.

The *Bridges* team always enjoys the celebration and the opportunity it provides to meet past and future story contributors at the event. It is a wonderful and awe-inspiring evening to see so many cancer survivors celebrating together.

Bridges continues to be a forum for cancer survivors and caregivers to share their stories of hope and survival. We welcome your stories at bridges@mskcc.org.



My Pet Therapists

By Johnny Cathcart

Johnny Cathcart is a two-time brain cancer survivor, filmmaker, and author living in New York City. He is a lifelong runner, Frisbee player, and advocate for cancer patients and survivors!

Mom wasn't happy when Dad and I marched through the backyard fence with smirks on our faces, followed by our new Dalmatian, Bell. She didn't want another dog; she was too heartbroken when the last one died and didn't want to have to go through that again. While we hated when Bell would wag her tail and knock things over or shove her wet snout in our faces, and were ripped apart when she passed, relationships with animals are special in a sort of magical way. We had two more dogs, two hamsters, and a ridiculously large and lovable cat named Mr. Mischief.

My life hit a hard wall when I was 12. Within a week of finding out I had a nasty ball of toxic cells mushrooming on my cerebellum, I had surgery and was diagnosed with a deadly brain cancer, medulloblastoma. Seventh grade just began, and I was to undergo a year of radiation and chemotherapy.

Teenage life is a rollercoaster in itself. Your body is going through changes and your heart and mind are transforming. So it wasn't easy when I came back to town, skinny and bald, sporting some greenish-yellow, Simpson-esque skin.

When the rollercoaster of life dips to such a deep and intense level, things change. I thank God that my rollercoaster eventually yoyoed me back up into life and chucked me out with a new perspective. Things had indeed changed. The air was clearer, and my overall sense of life was more potent. However, people's unconscious body language spoke to me more loudly. The distance between my life and the lives of healthy people seemed to grow. When a person hobbles through the subway doors on crutches, people immediately understand what's up and step aside. It's not as obvious when you're a cancer survivor. While I was in many ways just as disabled as a lot of folks with wheelchairs or crutches, no one could see that. Friends and family would be sweet and try to understand, but they couldn't. The isolation was overwhelming.

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ASK THE PROFESSIONAL

Sleep Strategies for Survivors

By Yesne Alici, MD

Yesne Alici, MD, specializes in psychosomatic medicine and geriatric psychiatry. She is the liaison psychiatrist to the neuro-oncology and 65+ teams at MSK.

What survivorship issues might impact one's sleep patterns?

A third of the general population is affected by sleep disorders, most commonly insomnia — perceived difficulty falling or staying asleep, early morning awakening, or poor sleep quality. Studies show a high prevalence of sleep disturbances in cancer patients that can occur throughout treatment and into survivorship. Many factors contribute to these disruptions, including physiological, psychological, and environmental issues; fatigue; depression; anxiety; pain; hot flashes; changes in bowel/bladder functioning; obesity; certain medications or substances; and hormonal therapy. Your clinician may recommend consulting with a psychiatrist or a sleep disorders specialist for further evaluation.

What are the risks and benefits of medication use for sleep in survivorship?

Several options have been shown to be effective in the management of sleep disturbances. The general recommendation is to use non-medication solutions to improve sleep and to use medications sparingly and for short periods. Prescription sleep aids and over-the-counter or herbal supplements are frequently used and can provide some benefit, but they have associated risks. When medications are used, the specific recommendation depends on the pattern of sleep disturbance, other conditions, potential medication interactions, past treatment responses, and side effects. Falls, cognitive impairment, dependence, and rebound insomnia are some of the associated side effects. Talk with your doctor about using any prescription or non-prescription sleep aids, including herbal supplements. Interactions between medications and supplements can occur that can potentially lead to reduced effectiveness and/or harmful side effects.

What alternatives can help improve sleep, and how would a patient access them?

The most commonly offered non-medication treatments are relaxation training, cognitive behavioral therapy, and sleep hygiene techniques. Relaxation training lowers arousal states that interfere with sleep and includes progressive muscle relaxation, guided imagery, or abdominal breathing. Cognitive behavioral therapy aims to change unrealistic expectations and misconceptions about sleep.

Sleep hygiene involves implementing healthy lifestyle practices that improve sleep, such as:

- Maintaining a healthy diet and regular daytime exercise
- Having a quiet, comfortable sleep environment
- Avoiding looking at the clock when you are awake at night
- Setting aside a worry time that is outside of night hours (instead of worrying in bed)
- Avoiding exposure to bright light during the night
- Avoiding caffeine, nicotine, alcohol, excessive fluids, spending too much time in bed, irregular sleep-wake schedule, daytime napping, activities that interfere with bed such as watching TV in bed, or stimulating activities before bedtime
- Using earplugs, white noise boxes, or relaxation tapes with nature sounds

MSK offers resources to those who experience insomnia and other sleep disturbances. Resources for Life After Cancer (RLAC) holds seminars on sleep issues; experts within the Department of Psychiatry and Behavioral Sciences offer consultation services to assess and manage sleep disorders through individual or group counseling; and the Integrative Medicine Department offers a variety of exercise classes and mind-body therapies.

Contact the Counseling Center at 646-888-0100 or Resources for Life After Cancer at 646-888-4740.



Silver Linings

By Lisa Healy

Lisa Healy is a former teacher and current CEO of her home with two awesome children, a loving husband, and three beautiful German shepherds. She is a lifelong parishioner and steward of St. Francis De Dales Church and passionate about spreading awareness for rare cancer research.

Living through the storms of crisis teaches us to appreciate the good times and to be grateful for the simple things in life. It can truly make us who we are. When I was young, I often told my family there were two things I wanted to be when I grew up: a teacher and a mom. I became an elementary teacher in 1994, and on May 2, 1999, I became a mother, as Lindsey Marie made her way into this world. It was the greatest gift and one I will cherish forever.

But just ten days later, I was diagnosed with Hodgkin's lymphoma. I remember the day well. I kept thinking, You can beat this, think positive, and do your mental affirmations. This strategy helped me compete when I was an athlete in high school and college and would help me fight the disease and live my life.

As I underwent weekly treatment, I had the support of my family, all of whom helped me during treatment with a ride into the city, a bag of healthy snacks, a note of encouragement, a babysitter for Lindsey, someone to go food shopping and even do my laundry. The teamwork was amazing and everyone helped so much, but even better than all that was the love of my daughter.

Once a week, after a long day of appointments and treatments, I would arrive home to Lindsey. I couldn't wait to see her. It was the most incredible feeling and brought me more strength than I can describe. I loved when she nestled into my embrace. After three months of chemotherapy followed by radiation, I ended up in remission.

As the years went on, I wasn't sure if I could have any more children because of the treatment. But

brought me life at a time when I felt like I couldn't do it anymore, and Ricky showed me how to live again.

As the years progress, I focus on the lessons I learned and the wonderful doctors, nurses, and people I met. I focus on wellness, seeing a naturopath, physical therapist, and trainer. I read once that the real source of suffering is not accepting what is in life. Now I accept what is and focus on all the silver linings the storm of Hodgkin's brought me. I have since joined a wonderful

“And once the storm is over, you won't remember how you made it through, how you managed to survive. You won't even be sure, whether the storm is really over. But one thing is certain. When you come out of the storm, you won't be the same person who walked in. That's what this storm's all about.”

– Haruki Murakami

on May 27, 2005, I gave birth to a beautiful, healthy boy named Richard Joseph. I felt so blessed and lucky to be given a chance to be that new mom I wanted to be in 1999 – walks in the park, rides in the car, shopping trips Lindsey and I never did. All of it would be brand new, and I was going to enjoy it!

Both children helped me to embrace the bad with the good, smile through adversity, never give up hope, and love whole-heartedly. Lindsey

organization that raises awareness and money for rare cancers by holding annual events and paying it forward to those in need. Even though a diagnosis might seem like a black cloud blocking out all sunlight, if you look closely at its edges, you might be able to see the silver lining.

Who will you choose to be after the storm? I am Lisa Healy, wife, mom, daughter, sister, niece, aunt, friend, daughter in-law, advocate, and survivor.



The Gift of Cancer: Gaining a Family

By Jeffrey Doynow

Jeffrey S. Doynow is a retired professional engineer and real estate developer/builder. He lives in Bedford, New York, with Carol Kurth, his significant other of more than 20 years. He has four children and a dog, Charrette, who along with Carol have given him support, energy, and will in his battle for survival.

I contacted the man who saved my life on January 18, 2015 — one year after I received a transplant of his stem cells. I learned his name, Miguel Estrella, and I called him in the evening. We spoke for an over an hour. Miguel grew up in a small Texas town and is an officer in the Navy, along with his brother, Bobby (his identical twin, I later learned). Miguel and Bobby took care of each other growing up.

We come from different places, and yet it felt like I had known Miguel for 30 years. We shared the same sense of humor and family values. At the end of the conversation, he suggested I call him again, anytime. We have spoken to one another every day since.

I was once told there's a gift to cancer, which I understood to mean that, in fighting for my life, I would gain perspective and emotional strength. But I got something extra. After a few months, I flew with my significant other, Carol, to Norfolk, Virginia, where Miguel is stationed, and we met his family. I've never known anyone so welcoming. Then in the summer, they came to visit us in New York, and we threw them a party. Everyone — my kids, my

sister, my parents — came. Bobby came too, and since then he's become as much of a son to me as Miguel and my own children. That's my gift. I got a new family.

In the time since, Miguel, Bobby, and my family have only gotten closer. I continue to visit them, and they continue to visit me and speak with all members of the family through text and phone. Carol and I have grown so close to them and their families. Miguel's young children refer to us as grandparents.

Miguel busts my chops for going to the opera, and I hassle him back for never finishing the 1960s, piece-of-junk Ford truck he's been refurbishing forever. When Miguel and Bobby are over, I'll joke to others that I like to keep my marrow source fresh, and also have a steady backup nearby. The two of them like to work on the house and fix things. I don't know why they think they owe us anything, when in fact, I owe Miguel my life.

I could've just thanked him that evening in January and left it at that. But I've learned that it isn't only your family that carries you through your most difficult days; rather, all

those that carry you are your family. Miguel knows it, too. So when this total stranger came to my rescue, there was really no question to either of us about the sacred place we would inhabit in each other's lives.

Miguel was promoted to full lieutenant a little while back, and I had the honor to pin him. I was unexpectedly named guest of honor. "I joined the bone marrow registry," Miguel's speech began, "and something wonderful happened."

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.

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
212-639-7648/212-639-8177



Sweet Red Pepper Soup

By Ellen J. Greenfield



In an effort to offer both practical assistance and emotional encouragement to current and recovering cancer patients and their caregivers, Ellen Greenfield created a compendium of soup recipes that pack the nutritional value of complete meals into a variety of tasty soups.

After a year of helping her husband undergo and recover from treatment for head and neck cancer, Ellen was motivated to create the cookbook when an oncology nurse at MSK remarked that the recipes would be a huge help to others in a similar situation.” It’s not news that nutrition is a huge factor in the body’s ability to find the strength to withstand trauma,” she says. “But while undergoing cancer treatment and recovery, nutrition is often the last thing one thinks about in any kind of practical sense. Surgery, chemotherapy, radiation – all of these stress body and mind, for patient and caregiver alike, and meals are often haphazard, if not skipped entirely.”

“Even after treatment has ended, cancer patients may be left with eating constraints,” she adds. “The body is looking for nutritional backup in order to heal, but the person may be hard pressed to take in sufficient calories to satisfy the need.”

Here is one of Ellen’s recipes – Sweet Red Pepper Soup – that can be served hot or cold. Enjoy!

INGREDIENTS

- 1/4 cup olive oil
- 1 large onion, chopped fine
- 2 carrots, sliced thin
- 1 stalk celery, chopped
- 2-3 cloves garlic, chopped fine
- 4 medium red bell peppers, seeded and chopped
- 1 large potato, peeled and chopped
- 8 cups chicken broth
- 1 6 x 4 inch strip of kombu (dried kelp), rubbed under cold running water to clean (optional, adds minerals)
- 1/2 cup cream or half & half

Sauté onions, carrots, and celery in oil until soft, about 8 minutes. Add garlic, peppers, and potato and sauté another 5 minutes. Add broth and kombu, if using. Bring to a boil and simmer 30 minutes, covered. Remove from heat and discard the strip of kombu. Add cream or half & half and puree. Soup can then be strained to remove any texture. Season with salt to taste.



Not If, But When

By Mike Philbin

Mike grew up in western Massachusetts and has lived in central New Jersey for the last 28 years. He works as an organic chemist, and his hobbies include photography, playing bagpipes with St. Ann's of Hampton Pipe & Drums, astronomy, fishing, and watching romantic comedies with his wife, Patty.

Prostate cancer had an early effect on my life. My father was diagnosed with metastatic prostate cancer in 1972 at the age of 55, and died two years later when I was 13 years old. In 2002, my older brother was diagnosed with prostate cancer and subsequently had a prostatectomy. He is still going strong today.

In May 2014, I had my third biopsy in seven years; the first two had been negative. During my follow-up visit to review the results, my urologist said, "First, let me say that you are going to be fine. We did find some cancer but we've caught it early and it was only in three of the 12 cores." He recommended that I follow up with Memorial Sloan Kettering in Manhattan.

The pathologist at MSK confirmed the diagnosis, and in mid August, I had a prostatectomy. I was up and walking within hours of waking up and was released the next morning. The pathology report confirmed that the cancer was confined to the prostate — a good first step. Up to this point, I really had little anxiety about the whole thing and people were amazed about how casual I was acting.

There was one bump on the road to recovery. Within a week of the surgery I developed a blood clot in

my calf (deep vein thrombosis, or DVT) and a blood clot in each lung (pulmonary embolisms). My MSK urologist had me watching for this post-surgical complication. Four more days in the hospital and a year of oral anti-coagulant therapy followed. I am not an overly religious person, but I found the Serenity Prayer to be helpful in taking things one day at a time.

In mid-October 2014, I had my first post-surgery PSA test, (prostate-specific antigen, an indicator of potential cancer). If my PSA was undetectable, I would be in good shape and would require no further treatment other than measuring my PSA every six months. Sure enough, it was undetectable. I wish I could bottle what it felt like to hear that news. I still have the message saved in my voicemail. Every once in a while I go back and listen to the message and smile.

In the months that followed, the anxiety that I had not experienced in the previous six months started to kick in. Not all the time, but when I least expected it, bam! There it was. While it made no sense — I was cancer free — I realized that it had been bottled up and was going to come out. I said to myself, "Why should I be anxious? I have had it relatively easy compared to other

people who have had to deal with cancer." This type of rationalization, of course, only made matters worse. I learned to meditate and find it to be very helpful in relieving my anxiety. Exercise, which includes playing my bagpipes (the ultimate core workout) is also a great help. The best thing, as it turns out, is a hug from my wife. I was very fortunate — through my three biopsies, the surgery, the pulmonary embolisms, all the doctors visits, and the delayed anxiety, my wife was by my side. We have gone through the deaths of our parents together and now this cancer "adventure." Each time we face adversity, it brings us closer together.

It's now more than a year since my surgery and my PSA is still undetectable. Days, even weeks, go by when I don't even think about having had prostate cancer, though I realize that it can and may come back at some time in the future. I guess it's good to keep my guard up a little.

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 Jackie Konkowski at konkowsj@mskcc.org or call 646-888-0800.

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Eight more weeks of chemo were followed by yet another scan, and the results are now in.

No coal this year. The new treatment is working. No new disease and, more importantly, the existing nodules have shrunk. To be sure, this does not ensure an imminent cure, or even remission. But in terms of the season, it is a gift that does not come wrapped and adorned in ribbons and bows. It does, however, redefine the holiday wishes for a happy and healthy new year.

There can be no doubt that our frame of mind after last year's results can't compare to the joy we feel this year. Ironically, at no time in the past year did we feel morose or defeated. We were always hopeful and never let the setbacks derail our optimism. No small part of our overall attitude came from knowing that Chris was being treated by the very best doctors, nurses, and scientists in the world. But more than that, Chris is simply a positive force of nature. Her spirit cannot be dampened. Cancer doesn't stand a chance.

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During the summer after that bout with cancer, I clearly remember sitting on the little red love seat in a small TV room of our old house and being really, really sad. My hands lay lifeless on my knees and my sniffles quickly turned into a compulsive cry of loneliness. I heard a creak around the corner of the doorway. I looked up with rolling tears, and there was Mr. Mischief. He waddled up as fast as he could, hopped in my lap, and started purring while lifting his paw to my chest.

While I'm sure Bell and Mr. Mischief didn't assess my hemoglobin levels and determine

the most effective direction in which to lob their tongues at my face, they had something that no other creature had. Those animals showed me something I needed: absolute, unconditional love and understanding. They were the ones that looked at me with the same smile and the same joy as they did before cancer.

Though both of them have long since passed, I'll never forget their impact on my journey through this crazy life. Cancer taught me to be tough, my family taught me to live, and my pets taught me how to see through veils of self-consciousness and love unconditionally.

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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.



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