Bridges

CONNECTING CANCER SURVIVORS

VOL. 12, SPRING 2011

A True Survivor

By Phyllis Kahn with assistance from Susan Glaser

Phyllis has used her artistic skills and love of nature to cope with physical challenges resulting from a childhood illness, a physical assault as a young adult, and her cancer diagnosis as an adult. As a teacher working with the special-needs population, Phyllis continues to reach many young people, sharing her zest for life and her love of the outdoors.

In the mid 1940s, when I was a child, I was hospitalized with encephalitis. I had neurological complications that included a seizure disorder, expressive aphasia, and partial paralysis. Despite recommendations to the contrary, my parents wanted me to receive intensive rehabilitation at home. Through diligence and the sheer will to succeed, I recuperated. I attribute my recovery to family trips to the countryside where I was able to blend my passion for nature and art. In the country, I immersed myself in the world of plants. Even a weed has a purpose! My observations of seasonal changes, colors, smells, sounds, and textures of plants gave my life meaning. Collecting plants and other earthly objects gave me the satisfaction to delight in my five senses. My artwork developed organically, bridging myself with the outside natural world.

At the start of my college years, I sustained a head trauma after a brutal assault. I was eventually able to make a heroic return and graduated with a degree in art and education. Subsequently, I received a master's in special education. My personal triumphs over neurological impairments helped me to integrate my love of art and horticulture into teaching special-needs children. Being a teacher helped me to encourage children to see these beautiful and wonderful natural forms. It gave me energy and excitement to share my passion with others. I also believed in the creative and therapeutic value of growing plants. The children loved to work with their hands in the soil, molding and nurturing something that could become an attractive contribution in a natural setting.

I was diagnosed with early-stage breast cancer in 1990 and was treated with surgery, chemotherapy, and radiotherapy. In 2002, I had endometrial cancer and underwent surgery and radiotherapy. Months later, during a follow-up exam, I was informed that my breast cancer had metastasized to the bone. I was then placed on an oral medication that continues to stabilize my condition.

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Memorial Sloan-Kettering Cancer Center

Editorial

by Eileen F. Gould

These days there are many ways to interact with fellow cancer survivors and patients. The Internet and social networks like Facebook and Twitter are revolutionizing communication. Now there is even a Web application to bring patients, physicians, and scientists together to collaborate on improving cancer care and treatment. These new methods of communication are empowering patients to become more involved both in seeking and giving advice.

While virtual communication is powerful and provides an expansive reach, it is comforting to know that more traditional methods of connecting with others are still available. For instance, the Patient-to-Patient Program at MSKCC (highlighted on page 6) offers a forum for newly diagnosed patients to speak with an MSKCC patient who has been down a similar path. No matter which method you prefer, sharing your experiences and listening to the experiences of others who have also been touched by the World of Cancer can be beneficial and therapeutic.

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

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Bird Watching

By Valorie Janice (1945-2010)

Valorie was a clinical social worker, psychotherapist, and chemical dependency counselor whose specialization was working with severely mentally ill or chemically dependent patients. Her great joy was helping people to heal and get the most satisfaction possible from their own lives.

Photograph by Michael Stubblefield

One of my greatest pleasures since my health challenge began has been bird watching. No matter what the scenery was from my hospital rooms, whether it was the business of the people and cars on York Avenue, or the apartment and office buildings staring me in the face on 67th and 68th streets, there were always the birds flying in the air, landing gracefully on a window ledge or building promenade. I found myself flying with them and enjoying the ride. I felt so free and at peace.

While recovering at home, I would stare for hours from my kitchen table or deck watching a variety of birds of a multitude of colors, enjoying the seeds in the feeder, chirping away in the bushes, and drinking water from the birdbath.

To me birds are symbolic of the freedom I feel, knowing that I am always being taken care of, and someday I will be as weightless as the birds, as I become free of the ailment that has temporarily taken away my freedom.

And then there were None

During multiple hospitalizations at Memorial Sloan-Kettering, I always found solace in looking out of the windows at the birds. Some were high in the sky, some landed on the window ledges of the buildings. However, in my last two-week hospitalization in July 2009, I saw none.

At first, I thought it odd, not one bird flying by when I looked out of the window. During this hospitalization, for whatever reason, I was less inclined to go to the window and look to my left, my right, or up in the sky for birds. Occasionally, I would look down in the street to see the activity of the people and cars. I saw no birds during that time.

I am not sure why, but I did not miss the peace and joy I found looking at the birds during past hospitalizations. Perhaps the pleasure I previously got from bird watching was within my heart and the fact that I saw none was not a concern.

Flying birds will always be symbolic of a great source of healing for me, whether on the window ledge or in my soul.

Ask the Professional By Tiffany Kendig, DMSPT, MPH

Exercises to improve stability if cancer and its treatment have affected your balance system

Tiffany Kendig, MSPT, MPH, is a senior physical therapist at MSKCC's Outpatient Rehabilitation Center. Her areas of interest include neurologic, balance, and vestibular rehabilitation in the oncology setting.

Q How do we maintain our balance?

A The balance system is composed of three different sensory systems that together provide information that helps us to maintain our balance. They are the eyes (visual system), the inner ear (vestibular system), and position sensors in joints and muscles (somatosensory system). These systems supply the brain with information about the position and movement of the body. Based on this information, the brain sends messages to muscles to make adjustments to keep the body stable and prevent falls. When any of these systems are affected, that will in turn affect your ability to balance.

Q How can cancer or cancer treatment affect my balance?

A Cancer or related treatments can impair balance when they affect any part of the balance system. For example, certain chemotherapies may damage nerves of the feet. This can limit one's ability to feel where the feet are in space or relative to the ground, making walking across uneven surfaces such as sidewalks or grass difficult. Depending on which systems are affected, you may notice that you are less stable in certain conditions or contexts. For instance, you may feel less steady on uneven surfaces, when turning your head to cross the street, or when moving in a dark movie theater. Balance problems can lead to falls, decreased confidence, and decreased functional independence.

Q If cancer and its treatment have had an effect on my balance, are there rehabilitation exercises that I can do to improve my stability?

A Notify your doctor if your balance is declining, or if you have any falls. Your doctor can rule out other potential causes for balance problems, such as medication side effects or visual deficits. If your problem relates to the balance system, your doctor can refer you to a physical therapist (PT) or occupational therapist (OT). The therapist will evaluate your balance and teach you rehabilitation exercises. Research shows rehabilitation exercises can help significantly. Under the supervision of your PT or OT, you can challenge yourself at a safe intensity without putting yourself at risk for falling. You should not perform balance exercises on your own unless cleared to do so by your doctor, PT, or OT.

Strength, flexibility, and endurance exercises help to improve balance. General strength exercises targeting core (e.g., abdominal, back, and pelvic floor) and leg muscles improve posture and stability. Stretching of major muscle groups facilitates proper postural alignment, decreases stiffness, and increases range of motion of joints. Foot and ankle flexibility allows for successful adaptation to uneven surfaces that could throw one off balance. Endurance training increases stamina and decreases fatigue, resulting in increased efficiency of movement. Your PT or OT can teach you appropriate exercises to address each of these areas as well as any weakness, muscle imbalance, or stiffness due to your cancer treatment. Together, optimal strength, flexibility, and stamina improve one's ability maintain balance and make quick, smooth postural adjustments to adapt to balance challenges and prevent falls.

Overall, a balance rehabilitation program will help to maximize your safety, confidence, and level of function. If you feel as though you may benefit from rehabilitation to address your balance problems, talk to your doctor. He or she can refer you to a PT or OT as appropriate.

Following Up

By Allison Margolies, MPA

Allison is a survivor of chronic myelogenous leukemia. She currently resides in New York, although she still considers herself a Bostonian at heart and is a proud Red Sox fan.

When I was diagnosed with chronic myelogenous leukemia (CML) in 1983, I was three years old. Lucky for me, I don't remember chemotherapy, radiation, and the devastating side effects of those treatments. Now, 25 years later, what I do remember is visiting my oncologist, Dr. W, at the Dana-Farber Cancer Institute in Boston month after month and year after year for follow-up appointments.

When I started working at Memorial Sloan-Kettering Cancer Center in 2007, a coworker suggested I look into the Adult Long-Term Follow-Up Program, which provides follow-up care for adults who had cancer during their childhood, adolescence, or young adult years. I immediately said no. How could I leave Dr. W? He saved my life and has been part of it ever since. We sent him holiday cards, we cheered him on as he ran the Boston Marathon to support Dana-Farber, and he even attended my wedding.

Being diagnosed with cancer is devastating. Every day is filled with uncertainty. You may think you are going in for routine blood work, but then you end up being admitted to the hospital because of a low white blood cell count. The one thing I could count on was the familiarity of Dr. W and his clinic. I wasn't just accustomed to my doctor — I knew the receptionist, I knew the nurses, and I even knew what stickers I would be rewarded with after I successfully finished my blood work. It didn't bother me that my choices of reading material in the waiting room were books about Elmo or Dora the Explorer. It didn't even bother me that when I asked Dr. W if his other patients experienced side effects similar to mine, he responded, "I don't know, because you're my oldest patient to survive a transplant."

Although I continued to enjoy my visits with Dr. W, throughout the next year I experienced more and more uncommon health issues, and my mother persuaded me to make an appointment at the survivorship clinic. I thought, well, making an appointment is not the same thing as making a decision. The day of my appointment with Dr. O, a physician and Director of MSKCC's Adult Long-Term Follow-Up Program, I felt shy, awkward, and anxious—three adjectives that are not normally used to describe me. Although everyone was friendly, I didn't know them and they didn't know me. But when Dr. O walked into the room, all of my fears washed away. What first struck me was his smile, and when we spoke, it was a conversation rather than a lecture. I was reassured that the many side effects I had been dealing with were, in fact, not rare, and we came up with a treatment plan based on his experience with patients in similar situations.

I anxiously called Dr. W the next day to tell him about my appointment. To my surprise and delight, Dr. W was thrilled that I had seen a physician in a long-term follow-up program. Survivorship is not his specialty, so he is not always aware of the latest research and protocols. While I had thought of him as a close confidant and friend, I had somehow forgotten that he was primarily my doctor.

The Hippocratic Oath states, "I will not be ashamed to say 'I know not,' nor will I fail to call in my colleagues when the skills of another are needed for a patient's recovery." While Dr. W was not afraid of my moving on to get the best treatment, I was. In life nothing comes easy, and being a cancer survivor is no exception. It was a mistake to think that now that I was no longer on active treatment, nothing was going to change and all my research about CML and cancer was no longer important or relevant.

What I learned is that I need to refocus my efforts on survivorship. I don't want to simply survive cancer, I want to survive it with conviction, a choice that requires making frequent changes to my medical team. These changes can be scary, time consuming, and frustrating, but I know they are beneficial to my health and well-being. I encourage all cancer patients and survivors to constantly reevaluate their treatment teams. Are you seeing a doctor because you know where the bathroom is, or because he or she can provide you with the best care? Don't worry — your own Dr. W will understand.

Paddling to Recovery

By Lauren Chiarello in collaboration with Sara Ritzler

Lauren is an energetic young woman who has dedicated her life to helping others. She manages MSKCC's fundraising programs Fred's Team and Cycle for Survival. She also participates in MSKCC's Stem Cell Transplant Orientation Sessions, where she recently became a Patient-to-Patient volunteer and patient speaker.

Sara is currently residing in South Florida while pursuing a career in hospitality management. She is active in the local chapter of the Leukemia and Lymphoma Society and the Junior League of Boca Raton.

We were bound to cross paths from the start. Sara Huie, Sara Ritzler, and I are young women with many things in common: age, height, relapsed Hodgkin lymphoma diagnosis, and treatment protocol. When we first met, I certainly didn't know we'd be spending an action-packed week together in Colorado learning to kayak for the first time with First Descents.

Let's back up a moment. In March 2009, Sara Ritzler and I sat across from each other during Memorial Sloan-Kettering Cancer Center's Stem Cell Transplant Orientation session. After the session was over, Sara was looking to connect with other patients and survivors in the New York area. We bonded easily over our shared diagnosis and became close during the course of our treatments.

Sara returned home to Florida after her treatments, and I continued my involvement with the Leukemia and Lymphoma Society's Team in Training program, speaking during corporate recruitment meetings in Manhattan. Enter Sara Huie. Well, almost. One day after I spoke, a young gentleman approached me and shared how his girlfriend had just found out she relapsed, and, would I mind chatting with her? Sara Huie and I met on a chilly day for lunch in early December and became instant friends. Sara Ritzler was in town the next month for her check-up scan, and we all went to brunch together. Over egg frittatas on the Upper East Side, we knew we had found "forever friends." In February, when Sara Huie was in the hospital preparing for her stem cell transplant, I learned about a program called First Descents – and I had to share!

First Descents is committed to curing young adults of the emotional effects of cancer and empowering them to regain control of their lives by experiencing outdoor-adventure therapy through kayaking, rock climbing, and other outdoor-adventure sports. And, there was no need for any financial worry, as the program is completely free. So, off we went!

The week-long camp promoted physical, emotional, and psychological healing and taught us how to white-water kayak on the Colorado River near Vail. After long and challenging battles with cancer, the opportunity to conquer something like class III rapids was a life-changing experience. It taught us that nothing, not even a cancer diagnosis, can prevent us from accomplishing our goals.

We look forward to experiencing many more equally life-changing adventures together in *the future!*

■ *Continued from page 1*

Surprisingly, I am not one to ask the question "Why me?" My energy is always directed forward, I have always had a lot I wanted to do. To me, physical limitations were simply obstacles to be overcome. They were never roadblocks to my destination.

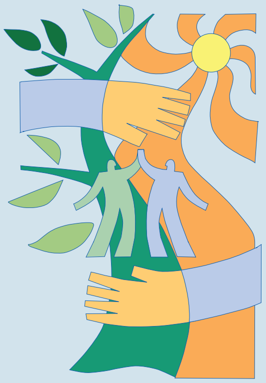
Recently, I completed a lengthy renovation in my apartment, which included consulting with disability experts and designers on enhancing my immediate environment with a layout that would enable me to remain independent as the years progressed. With both my physical needs and creative interests in mind, I developed a living space that was easily accessible and comfortable to live in. A studio with ample storage space was designed and I continue to create and review my work there. My windows overlook four beautiful trees on the street, which continue to give me joy and inspiration.

In spite of my many difficulties, my greatest desire is to share my personal experiences in the natural environment with others. Many have been touched by my fortitude and relentless determination.

Resource Review: Patient-to-Patient Volunteer Program

By Eileen F. Gould

The Patient-to-Patient Volunteer Program was started in the 1970s by an MSKCC physician and is currently managed by the Department of Volunteer Resources. It is a valuable resource that allows current patients to connect with survivors who have completed treatment at MSKCC. In order to volunteer, individuals must have completed active treatment and be in remission for a minimum of one year. Training for prospective volunteers focuses on providing helpful communication techniques and on teaching volunteers how they can draw upon their own experiences to support the needs of patients.



Often when someone is diagnosed with cancer, the fear of the unknown takes over. During this difficult time, it can be invaluable to speak with someone who has been through his or her own cancer experience and is willing to listen and explore the unknowns in a non-judgmental way. The MSKCC Patient-to-Patient Volunteer Program offers cancer survivors the opportunity to assist current patients by matching patient-volunteers with newly diagnosed patients. The peer support can be very beneficial in allaying patents' fears and anxieties. The interactions may vary in length and type, but whatever the interaction, the opportunity to use one's experience to benefit another can be enriching, therapeutic, and healing for both the volunteer and the patient.

While the Patient-to-Patient Volunteer Program has been in existence for 40 years, it has recently gained a coordinator who is devoted to expanding the program to include more volunteers who have been treated with diverse cancer types. If you are interested in learning more about becoming a patient-to-patient volunteer, please contact Marina Lenderman, LCSW, at 212-639-5329 or e-mail her at patient2patient@mskcc.org.

If you are a patient who is interested in being matched with a patient-to-patient volunteer, please call 212-639-5007.

Making Each Day Count

By FDK

Most cancer diagnoses come as a stunning and surreal revelation, but mine came as a confirmation of my inner voice.

One day, in our bed, my husband found an intruder in my left breast. Despite the fact that surgeons assured me that that tiny pimple-like feeling was not cancer, I kept pressing for more testing and a confirmation of my inner voice. After a complicated diagnostic process, it was determined that I did have cancer. My tumor was not the initial intruder my husband and I felt, but was growing right next to it. During this journey, I learned the importance of listening to myself and what I call the AEIOU.

A stands for ACTIVE listening. I actively listened to my body and my inner voice.

E stands for ENCOURAGEMENT and EMPOWEREMENT in facing the disease.

I stands for I. I knew my body better than anyone else.

O stands for OPTIONS. I weighed all of my treatment options before making decisions about my care.

U stands for UNDERSCORING the solutions and the possibilities that are best for me.

When a diagnosis of cancer occurs, we can either crawl into a corner and remain paralyzed or we can become empowered with knowledge: face the disease and turn our fears into HOPE. I was lucky my cancer was caught very early and I did not have to undergo chemo.

I am also grateful to God that I and other individuals facing the disease have been given the gift of today, and no matter how many obstacles we find along our life's journey, we have to hope and live the day: MAKE EACH DAY COUNT AND LISTEN TO OUR INNER VOICE. We have to remember that there is always a light at the end of a tunnel and hope that there will always be a light of longevity at the end of our journey. GOD bless us all!

Ask the Survivor: Why Do I Run?

Q *How Can You Go About Changing Your Diet and Exercise Plan Post-Treatment?*

By Robert J. Dwyer

Robert is a Manhattan father, grandfather, husband, and litigation attorney as well as a survivor of chronic lymphocytic leukemia and head and neck squamous cell carcinoma.

A Always one to look on the bright side of things, I appreciated my 40-plus-pound weight loss resulting from my chemo and radiation treatment after my modified neck resection for squamous cell carcinoma in April 2005. After all, it's tough to maintain your weight when your nutrition comes from injecting canned liquid into your stomach tube during the day and then "feasting" on tediously ingested chicken broth or creamed spinach at night. But, human weakness being what it is, as my ability to eat normal foods was restored, I put that weight back on over the next year, drawn by the lure of the foods I love (pasta, bread, cheese, ice cream, and so on). And I was still sufficiently weak from my treatment that I couldn't bring myself to exercise at all.

I began to miss my "smaller" self, and the arthritis in my left ankle was tweaking more and more just from walking. So I started on a chicken-and-fish, low-fat dairy, vegetable, no-snacks diet and an exercise program (stretching seven days a week, weightlifting plus 15 minutes of biking or running – weather dependant – three mornings weekly, and 25 minutes of biking or running another two mornings weekly). So now I've re-lost the weight. But that's not all I've gotten out of the program.

First, it feels great that I am in control of making myself better – not some doctor, medicine, or machine. I start most days with exercise and so reaffirm my existence. The warmth in my muscles that comes from the stretching, weightlifting, and biking/running literally tells me I am alive.

Second, it makes me feel better. The stretching makes me less creaky than I should be at my age. The diet and exercise work together to keep a spring in my step. And I find that I'm much more cheerful and alert on days that I exercise.

Third, the entire program works together. I'm less tempted to overeat or stay up late knowing that I'm running the next day, and the exercise actually seems to reduce my appetite. And whenever I've fallen off the diet-and-exercise "wagon," I know I have to stop overeating and restart exercising before I get too heavy or out of shape.

Finally, having a program like this gives you a window into your body. If you have a regular program, you'll know how you should feel every day, how fast you should run every morning, etc., and if you don't feel that way or run that fast, it's an early warning to you to see your doctor. I woke up one morning in early July 2009 and found I couldn't run worth a lick that morning. I was quickly diagnosed and treated for pericarditis, which, if left undiagnosed, could have progressed to more serious problems.

For health or taste reasons, not everyone will want to try my particular choice of diet and exercise combinations. But for many of you, there's some combination of diet and exercise that you'll like and be able to stick with, and that will allow you to enjoy the personal, physical, and emotional benefits of designing and implementing your own program.

Living Strong

By Lenny Paris

Lenny has been married to his wife, Jodi, for 16 years and is father to 12-year-old twin girls Kayla and Lindsay. He has been in remission from Hodgkin's disease for 20 years and continues treatment for mycosis fungoides.

I was diagnosed in May 1990 with Hodgkin lymphoma and three years later with mycosis fungoides. During that time I was finishing off graduate school and starting my career as an accountant. Up until then my life was free of any major illness and I was always in pretty good shape despite not having any regular workout regimen.

Several years passed and there was no recurrence of the original diagnosis and my overall health remained constant. However, I was trying to make exercise more a part of my life, so I bought a stationary bike to get started.

Then in 2003, I became inspired by the accomplishments of fellow cancer survivor Lance Armstrong. This coincided with my own search for an exercise plan that I could learn to embrace. When I took up cycling I started with a hybrid bike; some low-key rides and soon I was completely hooked. I have since become an avid rider and look forward to each and every ride.

It has become not only a way to get some physical exercise but also to clear my head, meet new people, and even raise money for **LIVESTRONG**, a cause that is vital to cancer survivors and an approach that MSKCC is finally embracing.

My overall well-being has improved as my mileage has increased. In 2010, I reached a personal best in terms of the most miles ridden in a calendar year, which included a **LIVESTRONG** Challenge in Philadelphia with Lance. I have found that this sport has enabled me to connect with other cancer survivors as well as given me opportunities to raise money to support the fight against cancer. This has been a very powerful part of my healing process.

Cycling has become as much a part of me as being a dad, a husband, and a cancer survivor. It has made me a better, more complete person.

Bridges is available to read online at www.mskcc.org/bridges.

If you would like to connect with other survivors through the Post-Treatment Resource Program, please see the online calendar at www.mskcc.org/livingbeyondcancer.

We are grateful for the support of our patients and family members. If you would like to be involved in volunteer efforts at Memorial Sloan-Kettering Cancer Center, please consider becoming a Patient/Family Advisor. We ask that patients be at least one year post treatment.

For more information, call the Department of Volunteer Resources at **212-639-8623**.

DEDICATION

Bridges is dedicated to all of the MSKCC patients who have endured many hours of arduous treatment and difficult challenges and, as a result, have become cancer survivors. The purpose of this newsletter is to offer a forum where patients and their families can share experiences.

Bridges is also dedicated to all of the MSKCC professionals who have worked in the world of cancer. These people have devoted their lives to making it possible for cancer patients to become survivors.

We hope that you and your family will share your stories with us.

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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.

Memorial Sloan-Kettering Cancer Center

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