

Bridges

Connecting Cancer Survivors



The Game Changer

By Kimberlie Ivey

As I jumped into the water for the swimming segment of the triathlon, a sound like a vacuum filled my head as I sank toward the bottom, a muffled silence that felt a bit dreamy as I headed toward the surface. As I burst through the cold air, sounds and a sense of urgency came rushing back and suddenly I sprang into action: “I hate this part; I have to get outta here!” Off I went, but I knew once I turned the quarter-mile marker I’d be headed back to shore. I made little deals with God to get there, but prayed to stay in the moment. The only way to get through it was to put the rest of the race out of my mind, otherwise it would seem insurmountable. As luck would have it, though, I blew out a tire in mile 14 of the bike ride and I was forced to exit the race. Disappointed, all I could think was, All that swimming for nothing? I hated that swim — and I really hated the unexpected, especially when I thought I had planned for it. People asked me why I enjoyed training for triathlons. It was an outlet, and I enjoyed the challenge, but I never knew just how I would end up applying it to my life.

My doctor said, “I don’t think that’s benign” as he handed me a picture of the large ulcerated mass in my rectum. That moment took me to that underwater, dreamy, urgent, ready-to-bargain-with-God place I knew. I fixed my gaze out the window of his office; he kept talking but I wasn’t

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Kimberlie Ivey is a native New Yorker, Kimberlie is also a wife, mother, and IT veteran in the financial industry. Her diagnosis at age 45 with advanced rectal cancer was a game-changing moment that required dramatic decisions and reshaped her world. Now two years cancer free, she enjoys yoga, writing, and spending time with her family and hopes to inspire others while transitioning into life after cancer.

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

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Memorial Sloan Kettering
Cancer Center



Editorial

By Eileen F. Gould

Above and beyond medical care, MSK offers many wonderful programs for cancer survivors. These include support groups in the **Resources for Life After Cancer** program, weekly art classes in the **Art Expressions** program at the Rockefeller Outpatient Pavilion, **Art Therapy** drop-in sessions at the Evelyn

H. Lauder Breast Center, and a writing group called **Visible Ink**. More details and contact information on these programs can be found under the heading of Patient Activities and Support at <http://www.mskcc.org/cancer-care/counseling-support>.

Another program within the MSK Department of Volunteer Resources, the **Patient and Caregiver Volunteer Program**, offers patients and caregivers the opportunity to meet others who have gone through similar medical situations and experiences. Make sure to read our Resource Review in this issue for more information.

Patients at MSK are cared for from the moment of diagnosis through survivorship. As patients and caregivers, we are fortunate that

MSK recognizes the significantly different medical and support needs along the cancer treatment spectrum. Even after patients complete active treatment, MSK offers a wonderful array of programs to fit their unique needs. We are fortunate to be at an institution that considers survivorship such an important and integral program in The World of Cancer.

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 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?

David Dorfman

Six years ago, I had just finished treatment for Hodgkin's lymphoma and ran my first triathlon—an Olympic-distance triathlon, a little more than 32 miles of swimming, biking, and running. Since then I've graduated to running Ironman triathlons (a total of 140.6 miles) and ultra marathons. I've also become a USA Triathlon Certified Coach and Race Official, a Certified Personal Trainer, and a Certified Cancer Exercise Trainer and joined the athletic staff at Princeton University. More importantly, I just had a daughter, Shoshanna.



Ask the Survivor

By Charlotte Barreda

Charlotte has worked for JP Morgan for the past 15 years; before that she was a political fundraiser for various federal campaigns. She earned her bachelor's degree from Rutgers University in political science and German studies. Having successfully incorporated exercise into her daily routine, Charlotte offered some insight into her own use of exercise and how she stays motivated.



When did you start exercising and what was your motivation to start? Did you exercise before you got sick?

I've always been fairly active and outgoing. When I was young, kids were expected to spend their days outside running around and climbing trees, but when I was 15 years old I was diagnosed with osteosarcoma of the right humerus [a bone that runs from the shoulder to the elbow]. After all of my surgeries — there were five in total — my lifestyle definitely changed. The doctors implanted a prosthetic in my right shoulder and removed muscles from my abdomen to rebuild it. After the reconstructive surgery, despite having a fabulously flat stomach, I couldn't even do a sit-up. As I began to recover, I started going to the gym regularly and managed to exercise with my new limitations. Being able to exercise helped me physically but also emotionally. It gave me the ability to restart my life and try to get back to where I'd left off. At the time, I really didn't appreciate how learning to exercise and finding the right exercise for me could change my life and redefine for me what it really means to survive.

What do you do to exercise and how do you incorporate it into your daily life?

I'm personally a big fan of kickboxing! It really makes you feel alive. I'm breathing hard, sweating a lot, and it really gets you pumped. I've also started spinning, which, for those who aren't familiar, is indoor cycling in a class setting. Depending on the season I also enjoy hiking, playing tennis, and riding my bike, and during the winter I cross-country ski. It is important to find something that you enjoy doing, though, because it's easier to find the time when it's doing something you love.

How has exercise affected your life? Do you feel limited by any late effects of your cancer treatments?

Exercise has given me the physical strength and confidence that my body can do (almost) anything anyone else's can do. I may have to do some things differently because of my limitations and it may take me longer, but I know that I can do it now and that's what matters.

My epiphany came when I was speaking with a massage therapist

and she said, "You can train your body to do anything with what you've got." So I started looking; my cholesterol was going up, I couldn't lose weight, and my doctors were telling me I needed to exercise my heart. That's when I decided to try kickboxing. Within six months my cholesterol was down by ten points and I'd strengthened my core. I could do a sit-up without holding onto the wall! Three years later, I have **never** been in better shape, and the constant pain I felt in my right arm has disappeared because I'm stronger.

Getting rid of the pain was huge as it allowed me to focus on other things. Pain is a constant reminder that something is not normal, and when the pain became secondary I could smile a lot more.

Have your friends and family joined you in exercising?

Yes, my sister-in-law and I go spinning whenever we can and I go skiing often with friends. Having their support is very helpful, but to be honest, being able to keep up with people who don't have any physical limitations feels really good!

Ask the Professional

By Lee Jones, PhD

Dr. Lee W. Jones is the Director of the Cardiology-Oncology Research Program at Memorial Sloan Kettering Cancer Center. He joined MSK in February 2014 after eight years at Duke University Medical Center.



How did you become interested in Exercise Oncology?

Growing up in northern England, I was raised to play and love football [American soccer]. As a result, I became interested in human physiology and biology, particularly the physiological responses to exercise. I studied sport and exercise science during undergrad and then continued my studies in Canada to focus more on patients who had suffered a heart attack.

While working on my PhD, the professor I worked for was just beginning to research the role of exercise in persons who had been diagnosed with cancer. We were primarily interested in how to initiate and maintain exercise levels in cancer patients but found out, to our surprise, that there was virtually no evidence even suggesting that cancer patients might benefit from exercise. As such, we started some of the very first studies in the field back in the late 1990s. At that time, the recommendation for cancer patients was to rest and recover following a cancer diagnosis — so for us to come along and propose investigation of whether patients should exercise was a radical departure from the standard of care.

Eventually, I became interested in two fundamental questions: First, how do cancer therapies impact the cardiovascular and musculoskeletal system, and does exercise protect against this injury? And second, how does exercise impact tumor biology? I started my own laboratory at Duke University, where I focused on these two questions in a variety of cancer populations. During that time, the level of evidence increased remarkably, but the field is still very young with many unanswered questions. In late 2013, I moved to MSK to take our research to another level; I felt that we needed to be at the best cancer institute in the world to achieve this goal.

What kind of research do you do at MSK?

Essentially, our goal is to produce the necessary evidence validating that exercise should become part of the standard of care for all individuals diagnosed with cancer. To do this, we aim to continue research that focuses on the above two questions. For example, in investigating the cardiovascular burden of cancer therapy, we recently published a study showing that adult cancer survivors who perform regular exercise have between a 30 percent to 50 percent reduction in the risk of cardiac events

[such as heart attacks] compared with patients who do not exercise after the completion of treatment.

We want to understand which patients respond best to exercise and what specific “dose” of exercise is best. Early results suggest that individuals with certain tumor types, who exercise following their cancer diagnosis may have better cancer outcomes than those who do not. We are now trying to understand if certain tumors respond better to exercise and what is the optimal “dose” of exercise to induce these responses.

How is exercise uniquely important for survivors?

Exercise is important for everyone, but we are still learning about the unique benefits for cancer patients and how best to prescribe it to them. In most circumstances, we do not yet understand how cancer treatment drugs impact normal cardiovascular physiology — and if we do not know this, then we certainly do not know how these organ systems are going to react to chronic exercise training. We are not yet sure how exercise may impact tumor mechanisms and how these effects differ between the different molecular features of tumors.

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Patient and Caregiver Volunteer Program

The Patient and Caregiver Volunteer Program offers Memorial Sloan Kettering patients and caregivers the opportunity to connect with others who have experienced a similar cancer diagnosis or treatment. We sat down with the program's coordinator, Maurisha Osi, to learn more about this unique resource.



What are some of the benefits of peer support?

It's important to emphasize that peer support is not professional support. Our patient and caregiver volunteers have been through challenges and anxieties associated with a cancer diagnosis, and the information they share with others is very personal in nature. Many patients I have spoken to who are supported by our volunteers emphasize how important it is to hear practical answers and insight from someone who has "been there"; some are also very thankful that many of their initial fears have been allayed by seeing and speaking with someone who lives a full life, particularly after a challenging procedure or treatment regimen. Many times patients feel isolated from family and friends, and having a chance to speak with a former patient allows them a place to speak freely in a discreet and nonjudgmental atmosphere.

How can a patient or caregiver connect with a volunteer?

A patient, caregiver or clinician can call or email for support using the contact information at the end of this article. A few demographic

questions are asked to determine the best patient or caregiver volunteer match; age, diagnosis, immediate circumstance or experience (i.e. newly diagnosed, young mother, upcoming surgery) are essential in making a good connection. Some patients have a very specific topic they would like to discuss, and others simply need a supportive ear from someone who understands. Caregivers also are able to discuss challenges and tips in caring for loved ones and receive ongoing support as needed. Introductions are conducted via phone and at times in-person. All patient and caregiver discussions are strictly confidential.

How are volunteers trained?

Prior to training, patient and caregiver volunteers review and are quizzed on eight MSK learning modules; which focus on information relevant to the volunteer role. These modules include topics such as, "Privacy Basics" and "Patient's Rights". Volunteers then attend a one-day training session to fully understand their role. They review privacy policies in order to learn how to handle sensitive patient information and practice communication techniques in interactive role play

sessions. They also review available MSK resources in order to share with current patients and caregivers as needed. Depending on the assignment, additional training is usually incorporated for inpatient floors and outpatient areas.

Is the patient or caregiver and volunteer relationship ongoing?

The duration of the relationship between volunteer and patient or caregiver depends on the circumstances and individuals involved. At times a person would like answers to specific quality of life questions and other times they desire ongoing support. It is entirely up to both to determine how and if they want to continue the supportive relationship, but many relationships last quite a long time.

What kind of confidentiality is there between the patient and volunteer?

During training new volunteers learn about protecting patient privacy and maintaining confidentiality. We use scenarios and quizzes to discuss how protected health information (PHI) should be kept safe. At the end of training, they are well versed

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present. I came up for air as my doctor was handing me surgical referrals. Sitting next to my husband, I thought, Oh, this poor man, *his wife has cancer*. I felt I had let him down.

I looked at my doctor and said, “What can I do *today*? I need to do something!” I was at the surface with the cold air and urgency. I needed to take action; I needed to swim, run, ride — anything.

I took care of all the “morbid” stuff leading up to the colonoscopy: my epitaph, my will and directive, and a beautiful story about love and life for my then two-year-old son. I cried. I was angry, sad, and resentful. I felt as though my body had betrayed me. I knew if there was to be a fight, the emotional stuff had to be

acknowledged and then shelved in order for me to get through it. Work now, cry later. That was how I trained, and now I needed to apply it in a very real way.

I called my mother, also a longtime MSK patient and survivor. All I managed to say was, “I’m sorry I have to tell you that they think your daughter has cancer.” I was so out of my body that I was genuinely speaking in the third person and felt like Rod Serling in *The Twilight Zone*. I felt like I dropped an anvil on her head. Whoever thought SHE would be helping ME with my cancer? My next call was to my father and I again issued another apology. I felt like the grim reaper with a contact list and a cell phone. As I would soon find in life, cancer

treatment, and sprint triathlons, no matter how hard you train or know that course, there are the unexpected blown tires. By handing the keys to my MSK team and the driver’s seat to God, this planner was now the passenger and the ride was about to begin. My surgical and oncology teams were assembled and armed with a plan. Confident, I was ready for the ride of my life. Then, just by chance, I learned from a fellow patient about a new trial — and as luck would have it, my case was a good fit. Always the planner, I wanted to know everything about it, but because it was so new there was very little information available. Treatment started, surgery followed. There were many blown tires, but I kept going.

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What is the best way to determine an exercise plan for me based on my personal medical history?

The overwhelming majority of information available on the web provides only very generic exercise advice. It is very difficult (and imprecise) to recommend exercise to anyone simply based upon their age or medical history. Think of it from a cancer perspective: We need to know about the type of cancer, the molecular mutations [of the tumor], and other factors before we decide on which treatment to prescribe. We take the same approach with exercise — it’s not one-size-fits-all. Really, the best way is to seek professional advice from a certified exercise specialist or

clinical exercise physiologist. These individuals will have the expertise to provide an exercise prescription that is individualized to your characteristics and preferences.

Are there any trials open right now related to your research that I might be eligible for?

Absolutely! Based on our current portfolio, we will have a total of seven exercise-training trials opening at MSK in 2015. These trials are being performed in a variety of cancer populations at various stages across the cancer trajectory — before a cancer diagnosis, during treatment, and following treatment. If interested, please contact the Patient Referral Line at 800-525-2255.

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.

Five Years... and Counting

By Gary Jorisch

Gary Jorisch, 64, lives and works in Long Island, New York. He was treated at MSK following the diagnosis of two separate cancers. Now that he has overcome one, he continues to fight the other with the help of the MSK staff. En garde!



Throughout our lives, we mark milestones by assigning anniversary-like values: Ten-year reunions, silver wedding anniversaries, and golden ones, of any variety. Among the sweetest, for cancer *cognoscenti*, is the one of five-year survival.

My 2009 diagnosis of prostate cancer now seems as distant as the first moon landing. Since that diagnosis there has been a second, unrelated cancer, which MSK treated as Julius Caesar would have — it came; they saw it; they conquered it. Not so the prostate cancer, for it persists and grows, with an annual march of more varied treatments, new side effects, and further encroachments on my quality of life. Yet in five years, there is a lot to be thankful for.

During these years the extraordinary care from MSK has allowed me to walk down the aisle with my son, Dan, and with my daughter, Renee. Those short walks in Chicago and Baltimore now loom long in my memory. I attended testimonials to my wife Sylvia's recent retirement after an exemplary 36-year teaching career,

and I passed a silver anniversary at my company and 37 years in finance.

I learned to dance freely under the moon, saw operas and ballets on the greatest of stages, attended symphonies and solos of world-renowned artists, and heard the unforgettable lines of Shakespeare uttered by the finest actor of our generation. I've missed meals while immersed in Mozart, become dreamy repeating a favorite Tchaikovsky polonaise, and felt thrilled learning the genius of Alexander the Great from a dozen texts.

I've developed and deepened interests in art and history through the aid of the best-written books and numerous museums. These have helped me appreciate the ingenuity of past civilizations and more recent periods in art, architecture, and design. While admiring many things of the past, I've not become blinded to a vibrant present and an even more beautiful future.

And there's the palliative effect of poetry. I've read many times the

Iliad and Odyssey, reveling in the words, the syntax, the stories of epic proportions that inform us even today. Who can dispute that I and my fellow MSK patients, as relapses mount and remissions fade, are like Odysseus, who "...wrecked yet again on the wine-dark sea, can bear that too, with a spirit tempered to endure...."

There will be losses along the highway of healing, but it is in our power to replace those losses and never look back. I have had to hang up my beloved baseball bat and glove, but in their place is gauntlet and foil as I fence the evenings away instead of following fly balls in the twilight.

My children asked my wife, "How is it that with all Dad is going through, he is so happy?" Her response? "I think he sees very clearly who and what is most important and so he loves and embraces those people and places and things that bring him the most joy." She is so right.

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My nurses became my personal trainers. They coached me through the hills, turns, and places to dig deep but also helped me change gears, signaling when I needed to pull back and take a time of active recovery. The biggest challenge was my ileostomy reversal (reconnection of the bowel). I had been looking forward to this being the end, but I had no idea how much of me it would take to recover from this procedure. While it remains an uphill climb most days, two and a half years later, I have come through cancer with no evidence of disease and with a whole new perspective on this race called life. I've found that the "new normal" is more of a daily journey than a destination for this rectal cancer patient.

As for my triathlon days, it will be a long road back. Realizing how much I disliked the swimming part of the triathlon opened my eyes to how much I truly loved cycling. That realization sums up my perspective on life. Even now as I train, there are blown tire days, but how I deal with them is very different. I have found that each part of this journey, regardless of how it feels, is necessary to get me to where I need to be. If I can see the gift at the finish line, it makes the rough parts of this path all the more satisfying to have conquered.

And there is always the duathlon.

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in identifying (PHI) and how to ensure things are kept confidential. Reviews are done intermittently to ensure this information remains fresh. A confidentiality agreement is also signed once someone is accepted into the program – this emphasizes that all information related to the program including discussions, is kept private and will not be shared.

How can I connect with someone or volunteer?

If you or your loved one would like to be matched with a caregiver or patient volunteer or you received treatment and/or cared for someone at MSK and are interested in volunteering in the Patient and Caregiver Program, please contact Maurisha Osi at 212-639-5007 or email patient2patient@mskcc.org.

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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.



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