



CONNECTING CANCER SURVIVORS

■ VOL. 21, SUMMER 2013

Beating the Odds

By Kurt Gibson

Co-Author Ellen J. Greenfield

Beating the long odds is something that Kurt Gibson knows a lot about: Since 2008, he has faced the challenges of stage III colorectal cancer and has also come back to help Team USA take the Gold Medal at the World Championships of Ultimate Frisbee in Osaka, Japan. This past October, his team, Doublewide, won the US Ultimate National Championship in Sarasota, Florida. Kurt's advice to himself and others: Stay positive!

I had just graduated from college in Florida where I majored in economics and played competitive ultimate frisbee, when I noticed blood in my stool and began to feel unusually fatigued. My performance on the field was still good, but competing and training at a high level seemed to take 110 percent effort, which just didn't feel right. Finally, I went for a colonoscopy, figuring it was just polyps that they'd remove and I'd be OK. Instead, tissue from the growth was sent to a lab for analysis, and they found cancerous cells.

Although I was living in Dallas, I came to MSKCC for treatment because of its

reputation as the best cancer center in the world and because I had family in the New York area who could help me during recovery.

During surgery, most of my colon was removed and I spent seven long days in the hospital. The doctors encouraged me to walk as much as I could, but the poor nurses were always chasing me down and yelling at me for not covering up my butt! Although that sounds funny now, at the time my whole body hurt. I felt like an old man all hunched over, and I was attached to three tubes and a metal pole on rollers.

After surgery, I learned that the cancer had spread to two lymph nodes outside the colon, which meant one thing – chemotherapy. Bah! I had 12 rounds of chemo over six months, and by the end I weighed under 150 pounds (I'm 6'2") and had trouble with cold sensitivity and loss of feeling in my hands and feet. I had a long way to go to get back to being the guy I was six months before.

It was really frustrating at first. I worked my way up from short walks to jogging and had to push myself to keep making progress until I could return to the

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Memorial Sloan-Kettering
Cancer Center



This issue of *Bridges* marks the fifth anniversary of our quarterly newsletter for cancer survivors. Thus far, 20 issues have incorporated over 80 patient stories and 40 expert and clinician essays on a vast array of topics that post-treatment survivors face many years beyond their initial diagnosis.

Cancer was often a death sentence in the 1970s when I was diagnosed the first time at age 21. So much research has been done and information shared during the 35 years I traveled through the World of Cancer Survivorship. Treatments are becoming more precise to improve outcomes, reduce toxicity, and provide better quality of life post-treatment.

MSKCC continues to be a trailblazer. It is at the forefront of identifying ongoing medical issues cancer survivors experience and developing strategies and therapies to address them. Survivorship is no longer an ancillary field of medicine; it is as important as the treatment phase.

It is a privilege and certainly an educational opportunity to be the Patient Editor of *Bridges*. I marvel at what lies ahead in the World of Cancer Survivorship as there are more than 13 million cancer survivors alive today in the United States.

I want to thank everyone who has contributed their time and energy to producing this newsletter including the patient writers, the experts and clinicians, the Advisory Committee, and the Medical Graphics Team. Your willingness to generously share your talents has made *Bridges* an award-winning publication.

I also want to thank our readers. Every issue is crafted with the goal of informing, inspiring, and validating you. We continue to welcome your ideas and stories at bridges@mskcc.org

Eileen F. Gould

Patient Editor
June 2013



Compassionate Care By Jane Madell

Jane was born in New York City and has lived here most of her life. She and her husband have raised two wonderful children who, fortunately, also live in New York, as do their three equally wonderful granddaughters. Jane is a pediatric audiologist, and is now consulting nationally and internationally after retiring from a wonderful career of more than 40 years working in hospital and clinical programs.

My family knows Memorial Sloan-Kettering well. My mother was diagnosed with breast cancer in the 1960s, at age 61. She had bilateral breast cancer. She also had a very bad heart. The surgeons at Sloan-Kettering knew that they had to get the cancer out in order for her to survive. She couldn't handle general anesthetic because of her heart, but they did not give up on her. Using a local anesthetic they were able to remove the cancer in both breasts and she recovered. She died many years later, but not from cancer.

I was diagnosed with breast cancer for the first time in 1994. On one level I expected it to happen, but you are never really prepared. The news was delivered six weeks before my daughter's wedding – not a good time to have a cancer diagnosis. My surgeon and oncologist were amazing. They understood the importance of my being as good as I could be for this very special event. I needed two surgeries and my first chemo before the wedding, but they scheduled it all so that I was feeling well the day my daughter walked down the aisle. After the wedding, I

proceeded with chemo, radiation, and genetic counseling. No genetic cause for my cancer was identified. Seventeen years later, I was diagnosed with breast cancer in the opposite breast. The staff was wonderfully supportive as I underwent surgery, chemo, and radiation again. They understood the emotional impact of getting cancer a second time.

Nine months after my second diagnosis, my daughter received her first. While she certainly did not want to go through cancer treatment, she knew she

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“You are a survivor now.”

Those were the very first words that I heard when I opened my eyes in the recovery room at Sloan-Kettering on an icy December day a few years ago. The moment that the nurse said this, I knew that my life would be changed forever. I’m a survivor. I’m one of the lucky ones.

While I was struggling through grueling chemo treatments, I couldn’t wait until this experience was a dim shadow in the past. I wanted to forget the doctors’ visits, the needles, the decisions, and the pain. But one day it struck me: Maybe it’s not meant to be forgotten. This experience is a part of the fabric of my life, like my children’s delivery dates or my wedding day or the day that my father passed away. It gives my life depth and it’s a tiny piece of who I am.

Sometimes in remembering, we grow and learn and heal. I hold the power now, it’s mine, and like so many other survivors who are fighting every day, I’ve earned it. So now when the sun sets, I stop and admire it instead of glancing up and continuing to run errands. When my friends call and ask me to meet for happy hour, even if I have tons of work piled up, I shut off the computer and meet them for a drink. When my kids talk to me, I listen. I look into their eyes and practice being in the moment.

At least once a month, I get calls from my friends and neighbors. They have just heard about another mom in the neighborhood who was diagnosed with breast cancer and we talk about how we can help with food or encouragement or rides to chemo. My friends want to know if the motivational e-mails they sent to me were helpful because they want to start sending them to this mom now.

On Saturdays in the summer, I can always be found watching my son’s baseball games on the fields around my neighborhood. During one early morning game, two women come to sit very close to me. “Please tell my friend that you’re better now,” one of the women says to me. The other wears a scarf on her head. So I share my story and tell her that there is light and life at the end of the dark tunnel.

As if a magic wand has been waved, the circle around us to becomes very quiet. Other people in the stands stop chattering about everyday life. They want to hear, too, and learn. “How can we help? What can we do?”

On that December afternoon in a busy hospital, those few words spoken by a nurse summed up a life-changing moment for me. I didn’t know it then, but now I realize that the responsibility is great, because I am a survivor.

■ *Continued from page 2*

was in a safe place. She felt the support of the staff.

Treating cancer is one thing. Treating the person is another. In the many years I have known Sloan-Kettering, I have been overwhelmed by the way

everyone who works there deals with the emotional side of this disease. I have seen people who are washing the floors walk up to someone who was crying and ask what they needed. I have been the recipient of that kind of support during times when I needed it. I know I have an outstanding group

of physicians who have saved my life twice, and that there was a wonderful group who saved my mother’s life and now my daughter’s. But they have done more than save our lives. They have helped us really become survivors – both emotionally and physically.

Ask the Survivor: Benefits of Qigong

By Carl Lehmann-Haupt



Q *Qigong is a practice of aligning breath, movement, and awareness for exercise, healing, and meditation. With roots in Chinese medicine, martial arts, and philosophy, qigong is traditionally viewed as a practice to cultivate and balance “intrinsic life energy” (qi). What prompted you to begin qigong? How long have you been practicing? What health benefits have you noticed?*

A I was 66 when I was diagnosed with throat cancer. The treatment was brutal: 39 sessions of radiation therapy followed by a radical neck dissection. My throat and tongue were so inflamed that I could no longer speak or swallow. I became as weak as a kitten. Though I got my voice back, I was left with a dry mouth and a strangely altered sense of taste. Thanks to a lifelong practice of medi-

tation I was able to resist the strong temptation to despair.

I had always been active, but over two years I had gone from walking two miles a day to barely being able to go ten blocks. The doctors said that I had spinal stenosis, which had caused both the weakening of my legs and the growing pain I was experiencing. When I got to the point where I could no longer sit, stand, or lie down comfortably, I contacted Dr. Yang Yang, a grandmaster of qigong and t'ai chi from China and an instructor in the Integrative Medicine Service at MSKCC, to ask if he could help. He showed me a series of qigong exercises that brought immediate relief. But because the pain was so acute I decided to have a spinal epidural, which cleared away the worst of the inflammation. I practiced the qigong exercises three to four times a day, and the problem receded.

I thought I was permanently better, and stopped doing the qigong exercises. All the pain returned, including

sciatica, lower back pain, and sore and weak hamstrings, so I made an appointment to have a second epidural. On the morning of my appointment, however, the *New York Times* broke a story about a batch of tainted medication that had paralyzed several people. I cancelled my appointment and applied myself to doing Dr. Yang's exercises again. Within a few days the pain had gone away.

“Keep moving,” Dr. Yang advised, “in every way you can.” Now I practice Dr. Yang's qigong exercises every day. As Dr. Yang emphasizes, traditional qigong includes both moving and still meditation exercises. The qigong has really helped to reduce my pain, increase my energy, strengthen my body, and improve my sleep, and, as Dr. Yang teaches, to embrace reality with a positive and healthy mental outlook. Because of these benefits I can still do other physical exercise such as riding my bike for a mile every day.

Learn more about qigong by viewing: www.mskcc.org/qigongvideo.

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sprinting, jumping, and overall endurance work that comes with being a top athlete. Believe me, it was not without setbacks. I am very fortunate to have had awesome care and encouragement from my family and friends. I could not have done it alone.

It took months of painful work, but I was finally able to rejoin my team, Doublewide, in 2009. We came up short of a National Championship in 2009, 2010, and 2011 and failed to qualify as the team to represent the

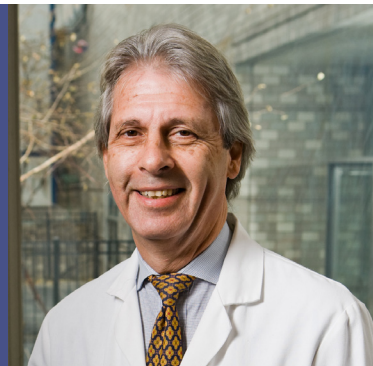
United States at the World Championships – an event that occurs every four years and is the pinnacle of our sport. Ultimately, however, I was invited by the coach of Team USA to play with the team in Osaka, Japan, where we won the Gold Medal. There is nothing more meaningful than to put on a USA jersey and represent your country at the highest level of a sport. The way it happened was a blessing from God after all I had been through.

As someone who knows what it's like to receive a diagnosis of cancer and to

struggle through the challenges of treatment and recovery, I want to tell others to follow your dreams and not to let cancer get the best of you. You have to control your attitude as much as you can and keep focused. Don't dwell on the things you can't control; focus on the things you can. And of course, have a positive attitude. Faith in God, my family, and my friends helped me make it through the way I did. Not only through the treatments, but to get back to my life the way it was before my diagnosis.

Ask the Professional:

Eye Health By M. H. Heinemann, MD

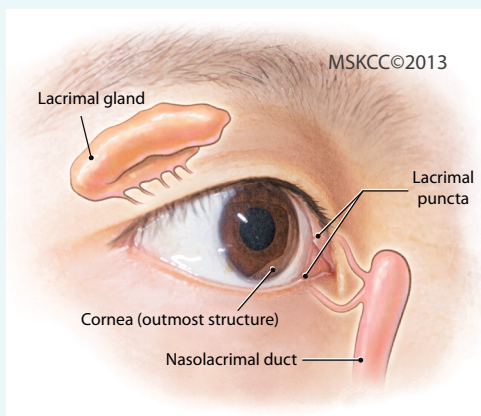


Q Some cancer treatments can affect eye health. Which treatments can potentially cause difficulties to vision?

A All types of cancer treatment can, and often do, cause ocular problems. Treatments such as chemotherapy, bone marrow transplantation, and radiation are all associated with ocular complications. Fortunately, most eye problems while not preventable are not permanent and can be managed. That said, serious, potentially blinding complications can and do occur. Symptoms such as blurred vision, tearing, and ocular discomfort may be due to minor problems, but may also be the warning signs of serious complications such as intraocular infection or structural damage to the eye and optic nerve. For this reason, timely eye examinations and good communication between the patient and the healthcare provider are vital. Some patients may also have preexisting conditions such as dry eye syndrome, cataracts, or glaucoma that might be made worse by the treatments they receive. A baseline eye examination before the patient begins treatment may be in-

dicated in these cases. Such examinations are often part of a clinical trial when the frequency and nature of treatment-related complications have not been established.

The most common ocular problems relate to the ocular surface and the relationship between the tear film and the cornea (the watch glass front of the eye). Reduction in tear production or a change in the constituents of the tears may cause blurred vision, discomfort, and even permanent damage to the cornea. Ocular surface disorders are common during chemotherapy, after radiation therapy, and as a compli-



cation of allogeneic bone marrow transplantation when graft-versus-host disease is a problem. Several factors contribute to such disorders, including inadequate tear production from the lacrimal (tear) gland and the accessory lacrimal glands in the conjunctiva, and reduced oil production from the oil-producing glands in the eyelids. The generous

use of warm compresses to the lids, artificial tears, and the occasional use of antiinflammatory drops are often effective. For patients with severe dryness, the simple insertion of cork-like occluders in the openings (puncta) of the nasolacrimal duct, which goes from the eyelid to the nose, can alleviate symptoms.

The field of chemotherapy is evolving rapidly. Some of the newest treatments using targeted chemotherapy and new classes of medications such as biologics have ocular side effects, which can range from abnormal eyelashes (trichomegaly) to fluid accumulations beneath the retina (serous detachment). Such complications can be managed, but patients should have thorough discussions with their healthcare team about potential side effects and symptoms to watch out for.

Some treatments, such as radiation therapy and certain types of chemotherapy, are known to contribute to cataract formation. The development of cataracts usually takes a long time. If cataracts do arise they can be treated with conventional surgical techniques.

In conclusion, patients and members of the healthcare team should be aware of the potential problems that cancer treatments may cause to the eyes. These problems can be managed, but prompt diagnosis is important.

Resource Review: Resources for Life after Cancer

Kimarie Boerger, LCSW, and Barbara Golby, LCSW

Many people, when told that they are finished with their cancer treatment, find themselves experiencing mixed emotions. Expecting to feel relief and joy, they can find themselves instead feeling lost, uncertain, confused, and alone. Worried by these unexpected reactions, patients do not always know where to turn for guidance and answers to their post-treatment-related concerns.

Resources for Life After Cancer (RLAC), part of Memorial Sloan-Kettering's Survivorship Initiative, provides guidance to help cancer survivors transition to life after treatment. Its support and educational programs address the emotional, physical, practical, financial, and spiritual impact of having been treated for cancer.

The program offers support and information through telephone consultations, individual counseling, and professionally led educational and support meetings. Monthly talks and workshops featuring experts from the Memorial Sloan-Kettering community and beyond address topics such as returning to work after cancer and managing common side effects like fatigue and neuropathy. Recent programs have included a workshop facilitated by social workers on dating after treatment and a lecture by Dr. Mario Lacouture from the Dermatology Service on the long-term effects of treatment on the skin, hair, and nails. For those unable to attend these programs in person, many programs are filmed and can be viewed at www.mskcc.org/cancer-care/survivorship.

Post-treatment groups, led by clinical social workers and nurses, are organized around specific diagnoses such as lung and colorectal cancers, and provide education and peer-driven support. There are also programs for special populations such as men, women, and young adults that give participants an opportunity to get to know their peers and explore new ways of adjusting to life after cancer. Many of RLAC's groups and talks are available online through MSKCC's Virtual Groups program.

You can learn more about our survivorship programs by calling 646-888-4740 or visiting www.mskcc.org/cancer-care/survivorship/resources-life-after.

My Experience Volunteering with the Patient-to-Patient Program

By Claudine DiSario

Claudine is an eight-year head and neck cancer survivor. She is grateful to her surgeon for her recovery and quality of life. She lives in Connecticut with her husband, Gerald, and three-year-old son, Bradley.



Have you recently been diagnosed with cancer? Are you feeling anxious and scared about your cancer treatment and recovery? Are you wondering what your quality of life will be like post cancer treatment? Are you feeling overwhelmed with questions and concerns that you can't easily discuss with your doctors, family, or friends?

If you answered yes to any of these questions, then I urge you to contact the Memorial Sloan-Kettering Patient-to-Patient Support Program. My name is Claudine and I'm one of MSKCC's Patient-to-Patient Support Program volunteers. I became a Patient-to-Patient Support Program volunteer approximately seven years ago, after my own head and neck

cancer diagnosis and treatment. It was very difficult for me to process all of my feelings after my own diagnosis. I was a bit intimidated by my doctors and had a tough time speaking with family and friends about my feelings. I was also very scared and afraid for my future.

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Paradise Found

By Gary N. Jorisch

Gary Jorisch, 62, is a geographer who spent five years in Africa and the Middle East before returning to Long Island to marry and raise a family. During his ongoing confrontations with cancer, his love of the ancient Greek arts has led him on an odyssey of such collections around the country. He believes we all have a muse — for life and for art.

As a survivor of one cancer and a fighter of another, I realize you may find it strange for me to write about paradise. Paradise, in our Western tradition, is that original place of perfection, of pleasure, of abundance, and, yes, innocence.

For survivors, most other people think that place is gone, vanished, or beyond reach. We have suffered along with our caregivers and are lucky and wiser to have returned to the same surroundings; maybe a little sicker, maybe a little sorrier, and likely looking over our shoulders a little more, echoing those lines of T. S. Eliot's: "The end of all our exploring will be to arrive where we started and know the place for the first time."

In Dante's *Divine Comedy*, paradise follows a period in purgatory. As survivors, we know something of purgatory. It is a place of anticipation, a place of waiting: waiting for news, waiting for results, waiting for anything positive after possibly years of disappointments.

But wait we do, through the mythical fire and ice described by Dante and the all-too-real fire and ice of toils, treatments, and sometimes a tiredness that ensnares both body and soul in the unforgiving vise grip of despair.

But there is always paradise beyond the purgatory. It is not the Garden of Eden variety I'm speaking about, with lush orchards of pomegranates, fields of figs, and crystal-clear springs. It is the paradise possible here — now.

For thousands of years there have been those who searched for paradise — adventurers, visionaries, explorers, conquerors — all of them looking in the wrong place. And still, after centuries of all that fuss and failure, there is no modern hyperlink to take you there, no map, no guide, no Garmin to point the way. But the paradise is within us, of a vision more vivid than can be described.

For survivors and those still dealing with the daily ordeals of treatments and

possibly the daily indignities of side effects, paradise is what you see when you close your eyes. It is those you love; it is those close to you in body and spirit; it is the memory of a kind word or act, a cake, a card, or a note of comfort.

I believe that survivors have found paradise. It may not be a place but a state of mind. The English poet John Milton wrote that "the mind is its own place for it can make a hell out of heaven and a heaven out of hell." Survivors have achieved that state of mind, that place of paradise. We have found it because of our experience, because of our caregivers, and because of those we love — and believe me it is a beautiful land, one that we do not want to leave.

Yes, for survivors there may be some earthly pleasures denied to us, but the pleasures of paradise — love, contentment, and beauty — are ours in abundance. Far from our problems making paradise lost, it has given us paradise found.

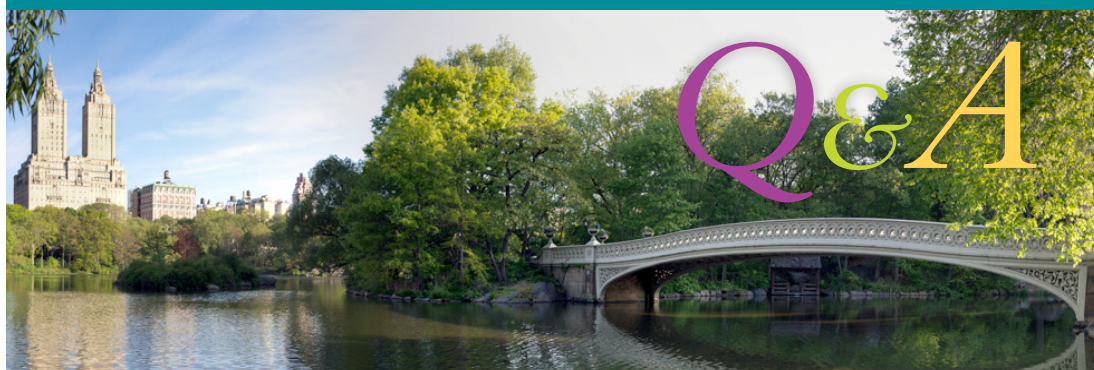
■ Continued from page 6

It helped me tremendously to speak with a volunteer from this program, whom I will call "Natalie." Natalie could relate to my anxieties and fears. I also found it helpful to discuss the treatment side effects and hear what she went through and how she managed to cope. A large reward that offered me hope was the understanding that, yes, this sucks, but it will end and I should be OK —

look at Natalie! I like sharing my own experience with others because speaking to Natalie aided me tremendously.

It's very rewarding for me to share my experience with other patients. I feel like I'm passing forward a community service that can help support and comfort a fellow patient in emotional need. I find that patients are usually elated to speak with me and many gain hope,

knowledge, and strength to endure the road ahead. I usually only speak with a patient once, but on occasion it's been a more regular dialogue. I urge all newly diagnosed patients to reach out to the MSKCC Patient-to-Patient Support Program. You might make a new friend who shares a similar experience to help walk a tough road ahead.



Photographed by Michael D. Stubblefield, MD

Test Your Knowledge

Question: Can I combine sunscreen and insect repellent?

Answer: Avoid the use of insect repellent in combination with sunscreen. Even though there are more than 20 products that combine insect repellent and sunscreen, the two should not be used together.

The sun-protective ability of sunscreen is decreased by about one-third when mixed with insect repellent. Also, since sunscreen needs to be applied generously every two hours, and repellents applied sparingly and no more frequently than every six hours, using combination products is not feasible or practical.

Of note, the most commonly used insect repellent is DEET, and its safety has been demonstrated over the past 50 years. Fewer than 25 cases of side effects have been reported in the millions of users. In fact, the American Academy of Pediatrics recommends the use of DEET in children older than two months. There is minimal absorption of DEET into the body, but when repellents are mixed with sunscreen, their absorption into the body may be increased, and consequently their side effects may be greater.

When the need arises to protect your skin from both the sun and insect bites, wear sun-protective clothing and apply an insect repellent containing DEET. Or apply sunscreen and use a repellent that you don't apply to your skin, such as clip-on mosquito repellents.

Answer courtesy of Mario Lacouture, MD

Duane Bailey-Castro, Cover Bridge Photo



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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.

PATIENT – TO – PATIENT

We are grateful for the support of our patients and family members. If you are a former patient or family member who has completed treatment please consider becoming a Patient-to-Patient Volunteer.

For more information, contact
Jennifer Wang at
patient2patient@mskcc.org.

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.

Visible Ink™ A one-on-one Writing Program for MSKCC 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.

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