

Jonathan's Leukemia Adventure

By Jonathan Edelstein

Hi. My name is Jonathan, and I am ten years old. I am being treated for acute lymphoblastic leukemia. When I was diagnosed I didn't really know what was going on around me. I met my doctor. He was talking about medicines for me and he was speaking what I call German when I don't know what they are talking about. Since then, treatment has gotten easier. One hard part was during the summer when I had anesthesia every Monday for five weeks

straight. I was feeling really good and just as I started maintenance I got osteonecrosis.

Osteonecrosis is when your hip socket collapses into itself like if you crush a Ping-Pong ball. I have been seeing a lot of doctors to get rid of it. All of it was hard except for the presents, which always put a smile on my face. After you go through cancer you turn into a warrior. That is my story of cancer. How about telling me yours?



Jonathan with his sister Bettina, who is 12 years old

Holding on to the Dream

By Judy Benjamin

*I had a great childhood, never sick.
In life we accept the good with the bad
and learn from it. God never gives us
more than we can handle.*

In 1980, I was twenty years of age when I was first diagnosed with rhabdomyosarcoma of the sinus area and muscle of the right eye. I had no idea what the word cancer meant. My dad explained chemotherapy the way radiation is given, not knowing

that chemotherapy and radiation are entirely different. I realized they aren't the same when I received my first chemotherapy treatment. Since then, I've gone on to have chemotherapy and radiation at the same time. I survived, and after twelve years I was

■ Continued on page 4

In this issue

- 2 Editorial & Ask an Expert
- 3 Ask the Professional
- 4 Holding on to the Dream
- 4 Bringing New Skills to the Workplace
- 5 The Accident
- 6 Trading Gowns

If you are interested in
submitting your story,
please visit
www.mskcc.org/bridges



Memorial Sloan-Kettering
Cancer Center

The concept of survivorship continues to grow beyond our expectations here at *Bridges*. Writers ages ten through 70 have shared their amazing personal stories.

MSKCC offers innovative programs and services to patients currently being treated as well as to survivors. The Patient to Patient Volunteer Program organizes current patients undergoing treatment to meet with survivors who have been down the same path.

The growth of knowledge from survivorship empowers cancer survivors to help current patients, and the value of sharing their experiences is immeasurable. Communicating with someone who has been treated benefits both the patient and the survivor. Not that long ago, it was hard to find survivors who wanted to talk about their cancer experiences with patients, especially for adolescent and young adults. But now, by using the Internet, a simple click of the mouse can put patients in touch with survivors anywhere in

the world who have had the same type of cancer and treatment. Long-distance friendships can form and experiences can be disseminated across the globe without even a face-to-face meeting.

Here at MSKCC, post-treatment programs geared specifically for survivors address both the physical and emotional repercussions of cancer and its treatment. A wide range of subjects, from how to get a job after cancer to how to deal with disclosing your illness socially, are discussed. The involvement of MSKCC survivors on committees in a range of areas, from the Quality of Care Initiative to the 65+ Program, illustrates the many possibilities for survivors to benefit others through sharing their knowledge and experience.

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



Ask an Expert: Managing Osteoporosis

By Elliott Kigner

Elliott is a retired high school science department chairman. Since retirement, he has been an active participant and course leader at the Stony Brook University Osher Lifelong Learning Institute. Elliott and his wife, Nancy, live and taught in Smithtown, on Long Island, but you will often find them in New York taking advantage of the city's many cultural and recreational offerings.

How did you learn that you had osteoporosis?

Being diagnosed with osteoporosis came as a shock, almost matching the feeling I had when I learned that my prostate biopsy revealed cancer. Before putting me on androgen replacement therapy after my prostate cancer treatment, my oncologist ordered a routine bone-density scan. Seven years prior my scan was in the normal range, and I had not been expecting any change. Upon getting the news, I immediately started thinking about what I had done to cause my bone loss. Had I not had enough physical activity or not gotten enough vitamin D?

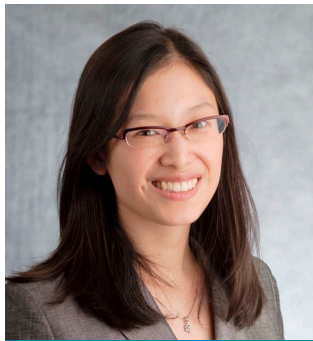
After your diagnosis, what did you learn about risk factors for developing the disease?

My sense of guilt was reduced when I learned that research has shown that medications that were essential for my prostate cancer treatment made me more susceptible to bone loss.

Additionally, I discovered that one of my cardiovascular medications also has an adverse effect on normal bone rebuilding. Finally, I cannot omit a consideration of a genetic predisposition to bone loss, which is out of my control.

How do you manage your osteoporosis?

After learning more about the causes of osteoporosis, I am focused on how I can take action to control the progress or even reverse this ailment. I will take a once-a-month dose of the bone remodeling drug, ensure that my diet includes calcium-rich foods (dairy, fish of the oily species, and salad greens), get plenty of exercise (walking, weight-bearing, and perhaps tennis playing again), and acquire the recommended amount of vitamin D (through sunlight in moderation, diet, and supplements). This plan calls for daily and unswerving attention. I know that the evidence suggests that such a regimen can halt the disease's progress and can offer me reason for optimism.



ASK THE PROFESSIONAL

By Hanna Rimner

Hanna Rimner is a senior physical therapist in the rehabilitation department at MSKCC. She specializes in exercise and osteoporosis.

Q What is osteoporosis?

A Osteoporosis is a “silent” condition in which one’s bones become weakened and prone to fracture. It can progress for many years without symptoms. The most common fractures due to osteoporosis are spinal, hip, and wrist fractures. A bone-density test can determine whether you have moderate (osteopenia) or severe bone loss (osteoporosis). An early diagnosis is important to reduce your fracture risk.

Q Which cancer treatments increase bone loss?

A Significant bone loss can occur as a result of hormonal treatments such as anastrozole (Arimidex®) or letrozole (Femara®), early menopause from ovarian failure due to chemotherapy or radiation, and allogeneic stem cell transplantation. The National Osteoporosis Foundation Web site (www.nof.org) also describes other risk factors for osteoporosis that are unrelated to cancer. If you think you are at risk, talk to your doctor about having a bone-density test.

What osteoporosis-related resources are available at MSKCC?

Q

A To help you optimize your daily calcium and vitamin D intake, Memorial Sloan-Kettering patients can schedule a free consultation with dietitian Kate Labzda Finnerty at 212-639-7071. You may also benefit from a referral to endocrinology for medication treatment options. In addition, your doctor may refer you to a five-week program offered by the rehabilitation department, which consists of educational sessions on exercise, diet, and medications, or to exercise classes led by a physical or occupational therapist

Q I have osteopenia/osteoporosis. How do I exercise safely and effectively?

A **Weight-bearing exercise** stimulates bone growth and improves bone quality, especially when you “surprise your bones” with out-of-the-ordinary weight-bearing patterns (e.g., low-impact aerobics, dancing, stair climbing, or walking at varying speeds, terrains, and inclines). High-impact exercise (e.g., running or jumping) is only recommended in children and individuals with normal bone density, as it can overload weakened bone. If your cancer has spread to your bones, check with your doctor about any weight-bearing restrictions.

Progressive resistance training stimulates bone growth. To ensure

proper form, professional instruction is recommended. Focus on strengthening muscles that open up the front of the body (e.g., military press and retraction) and avoid the “pec dec” and “lat pull down,” as these strengthen muscle groups that encourage slouched posture.

Avoid spinal flexion, as it may lead to spinal fractures if you have low spinal bone density. Also avoid any movement that involves bending at the waist (e.g., sit-ups, toe touches, bowling, using a rowing machine, or lifting with a rounded back). Instead, focus on lower abdominal strengthening with a neutral spine. The same principle applies to yoga and Pilates exercises: Omit spinal flexion exercises and focus on spinal extension exercises for the upper back.

Fall prevention strategies, such as balance exercises, tai chi and qigong, leg-strengthening exercises, and fall-proofing your home, can reduce the risk of extremity fractures.

Spinal fractures lead to stooped posture and kyphosis (humpback) and may affect your breathing and digestion. **Postural exercises** can facilitate healing and improve pain by unloading the fracture site. They should also be performed to improve function and prevent further spinal fractures.

■ *Continued from page 1*

pronounced cured. In that space of time I had a beautiful daughter who I was told would be born deformed or dead because of the strength of my treatment. Praise God, she is healthy. My head and neck doctor at the time told me radiation was the gift that never stops giving. I didn't know what he meant until I was diagnosed with squamous cell carcinoma of the palette.

I was treated with chemotherapy. I survived cancer once more by the grace of God. The cancer was bad the first time but worse the second time because I now had a four year old. I didn't know if I would survive for her to know me or for us to love each other.

She was a very smart child and had the understanding of an older child. While I was getting treatment, she would come to my bed and ask me if I wanted tea or water or some-

thing to eat. I hugged her every chance I got so she would remember me if I didn't survive. We got over that time in my life, and everything was going fine. I walked the Revlon Walk three years in a row, and in 2007, I carried the Memorial Sloan-Kettering flag.

In September 2008, I went to sleep feeling well; when I woke up the following morning I was very weak and dizzy. I didn't think much of it, but the entire day I felt the same way. I put off going to the hospital because of my phobia of needles. When I finally went in, I was diagnosed with radiation necrosis. It affected my speech and also the left side of my body. I cannot walk or use my left hand the way I usually do. I've had 35 hyperbaric treatments. I was supposed to have 40. I am currently taking therapy at NewYork-Presbyterian to strengthen my body and help me walk again.

I'm an independent person. I've made a lot of friends at Memorial Sloan-Kettering whom I consider my family. I presently am blind and deaf on the right side, I no longer have a palate, and I'm unable to chew. I have neuropathy and osteoarthritis in my spine and hand and necrosis damage to my left arm.

My daughter is now twenty and she makes me very happy. I believe that God tests our faith sometimes. I also believe that all of us can be survivors. We can all make a difference in this world. I am glad I had the first cancer when I was young, naive, and thought I could live forever. I now have a different outlook on life. I now believe that if we never lose hope for tomorrow, have faith in God, and hold on to our dreams, we can survive this disease. Where there's a will there's a way; God helps those who help themselves.

The Cancer Survivor: Bringing Skills to the Workplace

By Karla Layden



Anyone who has completed treatment for cancer or any serious illness, or who has cared for someone with cancer, has in effect run a small business. They have served as COO, CEO, chief accountant, traffic manager, human resources director — even public relations officer and IT analyst, researcher and marketer. These individuals may not have fancy

offices at AT&T, IBM, AIG, ABC, NBC, CBS, or any other alphabetic concoction, but this job description is just as challenging — and does not provide the benefits or resources. So let us examine some of the skills a cancer survivor acquires by just getting through treatment and follow-up:

- **Gathering and evaluating information**

With the Internet available to virtually everyone in this country, many survivors are going online to consult the myriad of Web sites offering information and weigh the value of each author's data. Some survivors prefer the hard copy version of this process and may conduct their research at a university library or medical school.

- **Presenting and persuading**
Survivors often present their research findings to healthcare providers and persuade them of its value. If the survivor has a good case, the provider will listen to reasonable arguments.

- **Listening and following instructions**

Anyone who has ever been ill knows that caregivers give them many instructions, almost none of which will be communicated in a written form. It is common practice now for patients to be accompanied to appointments by a friend or healthcare agent to take notes. There will come a time after the initial shock is worn off when you will hear instructions once and know just what to do. That is an acquired skill.

- **People skills**

Whether we believe it is right or wrong, people are not going to give us much slack even though

we are seriously ill. That gives us the opportunity to develop the people skills we need to manage not only our caregivers, but also the non-caregivers who are a part of life in the 21st century. These include accounting personnel, “customer care” agents of all sorts, colleagues, your children’s teachers, attorneys, etc. In fact, it is vital that we be able to fulfill our goals in tandem with these individuals. Unfortunately, just when we feel we most want to be coddled and cared for, we may need more than ever to stand up for ourselves. Just getting through treatment suggests that you as a survivor have cultivated the valuable ability to manage others.

- **Project management**

Managing your illness generally includes dealing with the costs of care as well as competing treatment options. The wisdom of Solomon crossed with the clairvoyance of a medium may help.

Managing an illness also requires wellsprings of patience and endurance that would daunt even the most determined Everest explorer.

- **Learning to delegate**

Recognizing challenges and finding ways to overcome them is a very important part of any job description. Delegation can be the difference between completing a project or letting everyone down.

- **Prioritizing**

Appointments and obligations of all kinds don’t go away because you are ill. The survivor learns to choose what is important and what just needs to get done.

A cancer survivor has to manage people, deal with budgets, read contracts and agreements, strategically plan for the future, and do it all under the worst circumstances.

IF YOU CAN DO THIS, YOU CAN DO ANYTHING!!!!



The Accident By Barbara Douglas Schacter

Barbara was born and raised in Brooklyn. Having recently lost Herb, her husband of 50 years, she moved to Manhattan from Queens and enjoys the proximity of her family, including a brand-new granddaughter. A retired elementary education teacher as well as pillow maker, she now spends her time writing, drawing, and playing the piano at the MSKCC recreational center.

In January 2003, I was awakened by a colossal explosion. I found myself in my car, racing toward a telephone pole. My foot slammed the brake and the car screeched to a halt. The car was filled with broken glass and my face was buried in an airbag. A tree had come through the back window, its branches banging against my head. I

was on the wrong side of a four-lane street at a bus stop. Miraculously no cars were coming and nobody was at the bus stop when I burst onto the scene. The street was littered with pieces of my car. An ambulance came and police too. People were yelling at me to get out. Finally, dazed but unhurt, I opened the door and stood up. “What happened?” No one could

tell me. I called my husband and the ambulance took me to the hospital. That was the beginning. I didn’t know what to think. Nothing like this had ever happened to me before.

Six days of nonstop testing proved nothing. In spite of the lack of evidence, the doctors believed that

■ Continued on page 6

■ *Continued from page 5*

something more than “dozing off” was involved in my accident. I went from doctor to doctor, specialist to specialist, and test to test. Weeks passed, then months.

Tired and disgusted, and with no answer forthcoming, I felt it was time to go back to my previous life. I started driving again and had no further incidents. Late on a Friday afternoon in September, nine months after the accident, I received a phone call from a neurologist who had previously ordered some tests. He said that one of my tests had been misread by his office and now, having discovered the mistake, he wanted the phone number of another doctor I had been seeing at Memorial Sloan-Kettering for what I thought was a totally unrelated matter. Within minutes the second doctor called me and insisted I come to his office early Monday morning for new tests. I went.

By Tuesday afternoon the results were in. I had a very rare disease, amyloidosis of the autonomic nervous system and needed a stem cell transplant immediately. After three

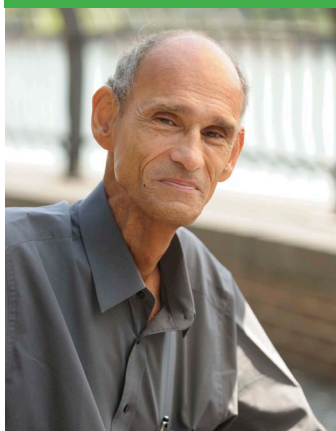
frenzied weeks of daily testing, I had an autologous stem cell transplant, i.e., my own cells were removed, purified, and then reimplanted. Following the transplant I was quarantined in the hospital for five weeks. The daily presence of my masked, gowned, and gloved husband and three sons made it bearable. I went home skinny, bald, and weak, only to be housebound for many months waiting for my immune system to come back. My hair, naturally reddish and straight, grew in blonde and curly. My taste buds changed as well, and eating became an adventure.

In time, a lot came back, including my original hair, my taste buds, my weight, and my energy. Slowly I started to feel like myself again. The next year, 2004, I received an invitation to the Stem Cell Survivor Celebration. There is something macabre about attending an annual party honoring your survival. A couple of hundred other survivors and I are actually so honored each October by Memorial Sloan-Kettering, where we received our stem cell transplants to treat blood diseases such as certain cancers and amyloi-

dosis. Approximately 15 years ago, before they started doing stem cell transplants, few amyloidosis patients would have made it to the second celebration. The whole ritual makes me uncomfortable because the stakes are so high. If someone you’ve seen at the party before isn’t there the following year your assumption gets pretty grim.

Don’t get me wrong, this is a joyful occasion with food and drink and music. Survivors come from all parts of the country to acknowledge and celebrate being alive. Friends and relatives are invited. Each survivor gets a dated T-shirt proving that we were there. Everyone smiles including me, but my clothes cover a body full of goose bumps.

Before stem cell transplants, there were only 1,300 people in the United States with amyloidosis; so few because the life expectancy from diagnosis was four to 13 months. Since the advent of stem cell transplants the survival time is considerably longer but still unknown. Our numbers increase while in the limbo of remission we watch and wait.



Trading Gowns By Ricardo Gesund, MD

Ricardo is a medical oncologist who did part of his training at MSKCC in 1985. He currently has a practice in his hometown of Cali, Colombia. He founded a special cancer prevention program that is dedicated to assisting poor people. The program was integrated into Cali's official health program and has more than 30 detection centers all over the city.

In April of 2006, I was feeling better than ever. Imagine my surprise when I noticed a lump on the right side of my neck. Since I had other lumps on my body — lipomas — I wasn’t worried

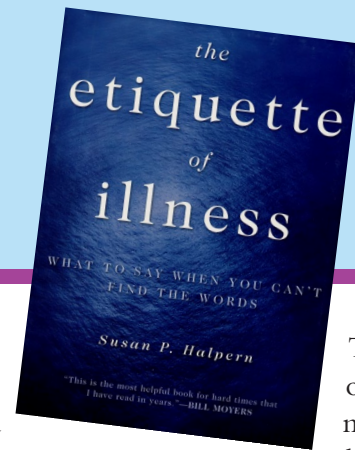
at the beginning, but in May the lump had gotten bigger and an aspirative cytology was done. To my dismay the exam showed a very aggressive type of squamous cell carcinoma.

One week later and 21 years after my training there, I was back at MSKCC — this time as a patient. After my first assessment, my doctor discussed the case with me and

■ *Continued on page 8*

Resource Review: The Etiquette of Illness

By Duane Bailey-Castro



In the face of a frightening illness like cancer, a caregiver's or friend's search for the right words and action can be a difficult task. In *The Etiquette of Illness: What to Say When You Can't Find the Words*, Susan Halpern offers an immensely personal and thoughtful guide to how people can communicate better, understand one another's needs, and learn to offer the best suitable support during an illness.

Heartfelt and candid, *The Etiquette of Illness* is remarkable in its grasp of the complex interpersonal relationship between patient, caregiver, and friends. Drawing on years of experience as a social worker and psychotherapist as well as a lymphoma survivor, Halpern argues that there is no single, silver bullet approach. Each relationship, like the individuals involved, is unique. "The particular person and the relationship dictates what words and actions are appropriate," Halpern believes. For example, she recommends that if you do not know the person well, give a card. If, on the

other hand, you are very close to someone who is ill, Halpern suggests volunteering to cook, watch a movie, read, or attend a play together. Sometimes just a simple hug, smile, or affectionate touch can be more valuable than anything. The bottom line is to listen to your heart. When you feel the urge to express your concern for someone, do so. Do not delay. Speaking about her own past, the author cautions, "Do something, do anything, or thirty years later you may find yourself writing a book on the subject, still full of regret for not contacting someone in some way."

To illustrate the diversity of responses that a family member or friend can have to the news of a loved one's illness, the author shares dozens of personal stories. Her aim is not to codify how to respond to a diagnosis, but rather to expand our awareness of the possibilities for joyful and mutual communication and intimacy. They serve as a useful guide for how caregivers and friends may or may not want to interact.

The success of such intimacy, however, depends fore-

most on open and honest dialogue. This is vital, Halpern argues, for the peace of mind of both parties. She asks caregivers and friends to trust the relationship they have developed and shared with that person. Don't run away. Respect your shared relationship by finding out what the person needs. "Listening closely, questioning, allowing the sick person to set the tone, take the lead, make the plan, is the greatest act of kindness," writes Halpern. Acknowledgement not avoidance of reality is what many patients seek.

Written for the caregiver and friends of a patient as well as for the patient himself, Halpern has contributed a refreshing and resourceful examination of how people can navigate this often tricky terrain. Her candid portrayal of survivorship will remain an indispensable guide for years to come.

Visible Ink™, Memorial Sloan-Kettering's writing program, offers patients the opportunity to work individually with a volunteer writing coach on a project of their choice, which need not be disease related. All current and former MSKCC patients are eligible, regardless of writing level or experience.

Each participant works with one of the program's 22 volunteer coaches to set goals, identify a project, and establish writing routines. Depending on individ-

ual needs and preferences, writing sessions can be held in person or remotely. *Visible Ink* participants have been remarkably productive, producing thousands of pages of written work. Projects to date include novels, short stories, essays, memoirs, articles, poetry, screenplays, comedy sketches, letters, journals, and blogs. Participant work has appeared in *Bridges*, *Newsweek*, and the *New York Times*. In addition, *Visible Ink* holds an annual staged reading of selected participant works and publishes

an anthology of essays, stories, and poems completed in the program. Writing is a powerful means to alleviate stress and enhance well-being. *Visible Ink* offers a positive, supportive framework in which patients can process difficult experiences, exercise their creativity, and share their thoughts and insights.

For more information, contact Judith Kelman, *Visible Ink*'s team leader, at 212-535-3985, kelmanj@mskcc.org or Judith.Kelman@gmail.com.

■ *Continued from page 6*

decided to take me into surgery. The cancer had advanced and compromised the lymph nodes in my neck; thus, I had to receive combined radiotherapy and the drug cetuximab. After three very hard months in New York City, not eating at all and feeling pain that I never thought could be endured, I came home. I had to relearn how to speak and how to eat. I had also lost all sense of taste. At least I had my mind!

Three months later, I started to do sports and eating was once again a pleasure. I was not able to give a lecture, but I could speak almost normally, so I went back to work. How I related to my patients changed completely. I was no longer interested in quantity. What was important was the quality of our relationship. I understood their emotional needs. Sometimes you need a harsh change in your life in order to learn. I had people involved in my treatment who did not even say hello or give me a word of support. They were always stressed and didn't "have time," but I also found wonderful

people who saw me through it. They were a great help. Moreover, the love of my family — especially my wife, who stood by me always — was a source of strength and encouragement. In December 2008, I was felt strong and healthy. I was swimming two miles almost every day. However, a routine PET scan showed a tiny spot in the liver. In January of 2009, I was back at MSKCC for surgery to remove the abnormal tissue found in my liver. Although, the surgeon was able to remove all of the disease, the pathology showed that the cancer had metastasized. The month I spent in New York City receiving treatment was difficult. The winter was harsh, and my operation a major one.

But here I am, back to life again, swimming, working, and "feeling better than ever." During this whole process, I learned that the mind is the most powerful instrument we have. I am very positive. I do relaxation, hypnosis, and self-hypnosis, I enjoy what life brings me every day, and I am not afraid of facing anything. That helps a lot.

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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.



Memorial Sloan-Kettering
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Bridges is a publication of the Memorial Sloan-Kettering Cancer Center Survivorship Initiative.



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