



## MY TRIP OF A LIFETIME

By Alexandra Capellini

*Alexandra is an eighth grader preparing to enter high school. She was diagnosed with osteogenic sarcoma at the age of seven, but that has not slowed her down one bit. Her hobbies include skiing and playing the clarinet. She lives in Brooklyn, NY, with her mom, dad, and younger sister.*

to build up my self-confidence and just have fun with other kids. I wanted the chance to attend the real Paralympics in China, to see other amputees and disabled athletes compete in sports and prove they are just as capable and good as everyone else.

After two months of anxiety, anticipation, and excitement, I received a call from the Paralympic Academy. I had never in my dreams imagined that I would actually be chosen as one of the 25 kids going to Beijing! I screamed and jumped up and down with my sister! Four months later, my mom and I were flying to Beijing! I was getting off on a plane with my mom in Beijing!

In China, we attended the Paralympic Games Opening Ceremonies in the Bird's Nest. I made great friends with the other kids from the Paralympic Academy, and these friendships I know will last forever. The Academy members, including my

mom and me, were able to go to the Water Cube and see swimming events, as well as tennis tournaments, wheelchair basketball games, track and field events, and track cycling! I had the chance to meet numerous Paralympians, who inspired me to believe that nothing can hold me back from achieving my dreams, not even being an amputee. One of the highlights of my trip was climbing the Great Wall with my mom and my friends from the Academy. One friend of mine, Roderick, was missing two legs above the knee. He didn't know if he could climb the Wall, but we both pushed each other to climb farther, and we did it! My experience in China was one that I will never forget. Being able to interact with people of the Chinese culture was another adventure of its own! The Chinese people were very hospitable and welcoming. To be honest, my mom and I cried when our trip was over; we had such a great time. Attending the Paralympics opened up a whole new world of opportunity for me, as an

■ *Continued on page 4*

Last year, I received an e-mail from a friend of mine at the Pennsylvania Center for Adaptive Sports. My friend told me that the Paralympic Academy was holding a sportswriting contest and would pick 25 children to travel as spectators to the Paralympic Games in Beijing, China. I have always loved sports, everything from swimming to rock climbing to tennis, and so I wrote my essay and sent in my application, hoping for the best. As an amputee, I have always tried to live by the motto "Live life without limitations." Through sports, I am able

### In this issue

- 2 Editorial & Ask an Expert
- 3 Ask the Professional
- 4 Protocol and Protocol
- 5 The Bakst Brothers
- 6 My Blond Wig

If you are interested in  
submitting your story,  
please visit  
[www.mskcc.org/bridges](http://www.mskcc.org/bridges)



Memorial Sloan-Kettering  
Cancer Center

Springtime represents a time of rebirth and renewal. For those of us here on the East Coast, it means we have survived another winter and there is summer to look forward to, with longer days and the warmth of the sunshine ahead.

As I write this editorial, *Bridges* has come full circle in publishing a year of quarterly issues. Our excitement grows with each new issue, especially as *Bridges*

continues to receive praise from fellow survivors, family members, and medical professionals. We have heard from readers near and far who enjoy reading the newsletter. Cancer survivorship certainly spans the globe and knows no boundaries. Whether reading *Bridges* in the lobby of MSKCC or on your computer screen overseas, we hope the courageous stories of cancer survivorship continue to resonate with you as hope springs eternal.

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



Eileen F. Gould, Patient Editor

## Ask an Expert

### Utilizing a survivorship Listserv as a resource

Linda Zame, moderator of the long-term survivors group within the Association of Cancer Online Resources (ACOR), online at [www.acor.org](http://www.acor.org), shared her expertise on electronic mailing lists, commonly known as Listservs, with Jennifer Ford, PhD, during a phone interview on December 10, 2008.

#### About Linda:

Linda was diagnosed with Hodgkin lymphoma in 1972 at the age of 21. After experiencing a variety of physical problems, she ventured on to the Internet and found two long-term survivors with experiences similar to

hers. It was then that she began to realize that her symptoms were related to her prior cancer treatment and that connecting with other survivors would be beneficial. In 1998, she found a handful of survivors on the Internet and gathered them together, which was the beginning of the ACOR long-term survivors group.

#### How are Listservs useful for cancer survivors?

Listservs can be quite useful in many ways. They are helpful in allowing survivors to connect, especially those who are geographically isolated. A Listserv can also help survivors obtain and share information, understand their potential health risks, learn how to better care for themselves, learn how to deal with health concerns and symptoms, and obtain advice on how to cope. For me, it was a relief to find other survivors with similar stories to mine so I could hear about what others were doing and how they were dealing with a particular issue. I believe that life is much easier when you are in a group.

#### How does one find a Listserv?

One of the most important things to assess is whether the Listserv meets your needs. As a member, you should feel heard and responded to in a respectful way. Research the organization (e.g., ACOR, Yahoo) hosting the Listserv to ensure it is legitimate. Seek out a Listserv that has an active moderator.

#### How do you suggest someone find out about a Listserv moderator?

Don't be shy to ask the moderator about his/her background. A good moderator should have a group of physicians who can help answer questions posted by Listserv members. You will also very quickly get a sense of how involved a moderator is after participating in the Listserv. If the moderator appears absent or the Listserv is disorganized, people are disrespectful, and/or you receive a lot of spam, it might be time to look elsewhere.

# Cognitive Changes Associated with Chemotherapy

*Tim Ahles, PhD, is a behavioral psychologist with a special interest in the cognitive effects of cancer treatments. His work focuses on cognitive-behavioral interventions designed to improve symptom management (e.g., cognitive problems, pain, and sleep disorders) and to reduce stress associated with cancer and cancer treatments.*



**Q** | What is “chemobrain”?

**A** | Chemobrain is a term coined by cancer survivors to refer to changes in cognition (the process of thought) following treatment with chemotherapy. The most common cognitive problems reported are in the areas of attention and concentration, short-term memory (the ability to remember or learn new information), and the ability to multitask. Many people report that chemobrain comes and goes (there are good days and bad days) or that they are fine if they have only one task, but begin having problems if there are multiple tasks, distractions, or time pressures/deadlines. The cognitive changes are typically subtle in that friends and family are often unaware of the changes. However, these cognitive changes can be very important to the individual experiencing them because changes in cognitive functioning can influence their ability to accomplish day-to-day and work-related activities. In part, the impact of chemobrain depends on one’s life demands. If a person is working, has young children at home, and is responsible for organizing a household, then any change in the ability to multitask may be very problematic. On the other hand, if the person is retired and has

a more relaxed, flexible schedule, then the impact of chemobrain may be less dramatic.

**Q** | Does everyone experience chemobrain, and how long does it last?

**A** | During chemotherapy, almost everyone experiences changes in cognitive abilities because of the acute effects of chemotherapy. However, the majority of people report gradual improvement in most chemotherapy-related side effects, including cognitive abilities, over six to 18 months post-chemotherapy. However, 20 to 25 percent of survivors report that they only recover to 70 to 80 percent of their pretreatment level. For this group of survivors, the change in cognitive functioning seems to be permanent. However, the one bit of good news is that these changes seem to remain at the same level and do not get worse over time.

**Q** | Is chemotherapy the only cancer treatment that influences cognitive functioning?

**A** | No, there are several types of cancer treatments that can cause changes in cognitive

functioning. For people with brain tumors, surgery and radiation to the brain can cause severe cognitive challenges. Additionally, we know that sex hormones (estrogen for women and testosterone for men) are important in maintaining normal memory functioning; therefore, treatments that influence these hormone levels can influence cognitive abilities. Examples include tamoxifen or aromatase inhibitors used in the treatment of breast cancer and androgen ablation used in the treatment of prostate cancer.

**Q** | Are there any treatments for chemobrain available?

**A** | Unfortunately, we do not have specific treatments yet; however, researchers are studying two approaches: medications and cognitive rehabilitation. A variety of medications that activate the brain and reduce fatigue (a common coexisting problem) are being studied. Ritalin is an example of this type of medication. Cognitive rehabilitation means teaching people strategies that help to make up for their cognitive problems, such as memory aids (calendars, lists, Palm Pilots), organizational skills (placing the car keys in a basket near the door), and time- and stress-management skills.

■ *Continued from page 1*

amputee. I still keep in touch with the kids from the Paralympic Academy. We still joke that someday we will all come together again and go back to China!

We miss being in China and having each other for support, because we were all “physically challenged.” However, I do not think any of us are limited in any way. We know that there is opportunity

for us out there, and we refuse to let our physical situations stop us from achieving our dreams. As for now, I stand by the quote that defines me, “As an amputee, why not get out there and do it all?”



*Alice with His Excellency, Mr. BAN KI-moon, Secretary-General of the United Nations*

## Protocol and Protocol

By Alice Hecht

*Born in Belgium in 1949, Alice has been working for the United Nations both in New York and in various other countries since 1974. She is currently the Chief of Protocol of the United Nations. She is married and has one son and one grandson.*

If you are reading this article today, most likely in the waiting room of Sloan-Kettering, it means that either you or someone close to you is on a protocol (treatment regimen) designed to help cure or control your specific type of cancer.

I happen to live under two types of protocols. Since May 2006, I have been on a medical protocol of a weekly treatment of Herceptin and Taxol, for breast cancer with metastases in the bones, stage IV. I have been, over the same period, the Chief of Protocol of the United Nations, where I am responsible for ensuring observance of etiquette and a set of rules that prescribes good manners in diplomatic life. As Chief of Protocol, I organize the visits of heads of states, prime ministers, His Holiness the Pope, and other VIPs, as well as the official life of the Secretary-General.

A medical protocol is a treatment plan (either research or standard care) devised for a specific medical condition. Diplomatic protocol is about respecting rules and procedures recognized by all parties involved as those to be followed for good order. The approach and objective of both protocols are similar in their attempt to provide clear and detailed guidance when dealing with a specific situation. But while a medical protocol is ultimately

about avoiding death, diplomatic protocol is all about the gentility of life.

My first bout with breast cancer came in August 2000. Found on a regular mammogram, the tumor was only six millimeters. The radiologist had recommended that I come back the next day for a needle biopsy but suggested that I make an appointment immediately with a breast surgeon. My life suddenly broke in two distinct parts: the life “before” and the life “after.”

That August morning was one of those hot, steaming New York summer days. When I walked out from the darkness of the doctor’s office into the blinding brightness of the day, I remember that the sidewalks were glimmering like diamonds under the sun, crowded with people running about their lives, with their headsets, their shopping bags, their briefcases — walking about as if everything was normal while I had just been branded with the word “cancer.” How could they not know what was happening to me? How could they enjoy life while I, who swam every day, never smoked, had a glass of wine only once a week, put money in my savings account, had no debt, had been pushed by an unknown evil from the threshold of health to the brink of death? How could they not see the terror on my face and the word cancer burning on my forehead?

How could they just go by and ignore me? I was the center of the universe, and no one noticed me.

In my dizziness, I wanted desperately to keep living as if the word cancer had never been uttered to me. Cancer was a word that I had always avoided, as if just to say it gave it power. My life was thrown in the middle of a world shadowed by a horrible disease. The world of the living and the world of death were colliding. Cancer made time stop. The future had been taken away from me.

Two weeks later: a lumpectomy and a diagnosis of clean lymph nodes, nothing in the margins. The follow-up protocol was simple: I would need six weeks of radiation, daily tamoxifen, and six monthly visits to the oncologist. I breathed again. No chemotherapy. No falling hair. No nausea. No tiredness. I could live with that protocol and get the constant humming “cancer” maybe not to disappear but to quiet down. The rest of the world could come back to life with me in the middle. I silently thanked the medical profession for devising a protocol that would pull me out of this nightmare.

*The remainder of Alice’s story is published online. Please visit [www.mskcc.org/protocol](http://www.mskcc.org/protocol) to continue reading.*





Harrie (left) and Richard (right)

# The Bakst Brothers

Richard and Harrie Bakst

*Harrie, 24, and Rich, 27, grew up in the Riverdale section of the Bronx. Both attended New York University. Harrie is the president and founder of Carnegie Sports Group, a consulting group specializing in corporate social responsibility and cause marketing that is based in Manhattan. Rich is a first-year resident in radiation oncology here at MSKCC. Both Harrie and Rich run for Fred's Team, a group that participates in running events to raise money for cancer research at MSKCC. To date they have raised more than \$18,000 for head and neck cancer research at MSKCC.*

2007 was set to be a great year for the Bakst brothers as both of us were graduating from school, Harrie from college and I from medical school. My year began with residency interviews during which I had the privilege to interview at MSKCC. What I never could have imagined that interview day was returning to the hospital one month later for Harrie.

As a member of a scholars program, Harrie was to go on a trip abroad with faculty and other classmates over spring break. While Europe was the initial plan, it was later changed to South Africa. When I heard of the change, I insisted that Harrie go to my primary care doctor for immunizations. Harrie was seen the next day for shots, and the doctor, miraculously, did a complete physical exam despite Harrie having not a single complaint. The doctor detected a painless lump under Harrie's neck, which he had been unaware of. A subsequent visit to an ear, nose, and throat doctor revealed that the lump was a very rare malignant salivary gland tumor — a tumor unheard of in a person so young. With that, our worlds were turned upside down.

The subsequent months were the worst of both our lives. Living together in our small apartment, the anxiety, fear, and emotions surrounding the numerous doctor visits and upcoming surgery

were palpable. The word courage does not do Harrie justice. At only 22, and after only a brief hug, Harrie marched into the operating room without a hint of fear in his step. I, on the other hand, wasn't as stoic and walked back to the waiting area near tears. However, the real tears came four hours later when the surgeon informed us that the operation was a success. Harrie recovered so well that he was back jogging one week later. However, Harrie subsequently faced his own personal marathon: a six-week course of radiation treatment that promised to have significant side effects during the treatment period including severe fatigue. What the radiation oncologist failed to realize as she discussed the side effects was that Harrie's spirit was immune. Not only did Harrie greet each visit with a smile, he attended his final classes, took his exams, graduated, and ran three times a week during this period. In other words, Harrie was unstoppable. I knew early on in Harrie's radiation treatment, in May, that he would run the New York City Marathon in November, now that he had already overcome his own personal one. We signed up together for Fred's Team during Harrie's radiation treatments, which ended June 5, 2007. Harrie attended his first Fred's Team training run later that month. By November, Harrie had a clean bill of health, a wealth of strength in his legs, and a newfound purpose. While the

hair that he had lost during radiation had finally grown back, a patch of hair was shaved on the back of each of our heads on marathon morning — a visible reminder of Harrie's first marathon. We set out on November 4, 2007, on a mission to cross two finish lines together, the first and most important one right here on First Avenue.

We ran the marathon with Fred's team because we believe in MSKCC and are forever grateful to the Center. We ran together because Harrie had to go into that operating room alone. We ran over the 59th Street Bridge to First Avenue together because for 33 days last spring we took cabs up that same street early in the morning before class for radiation sessions. Most importantly, we ran the marathon with each other and for each other. And so 2007 concluded in the best way imaginable, with both Harrie and I crossing both finish lines, triumphant, hand in hand.

However, that finish line was the start of something amazing for the Bakst brothers. Since then, we ran the New York City Marathon again in 2008, and to date, have raised over \$18,000 for head and neck research at MSKCC. We also participate in Rock & Run on the River, a 5K run/walk that benefits survivorship programs at MSKCC. Further, Harrie has also been

■ Continued on page 6

the most influential person in my career as a physician. Last year, during my internal medicine internship at Mount Sinai, I decided to change specialties. I wanted to do for others what the doctors at MSKCC had done for my

brother, and I decided to pursue a career in radiation oncology. As of July 2008, I have begun my residency training here at MSKCC. Harrie, too, has moved onto amazing things, as the president and founder of Carnegie Sports Group, a philanthropic consulting company, whose

efforts have helped many charitable foundations, including MSKCC. Harrie and I have now come full circle. We cannot imagine our lives without cancer, but are dedicated to helping create a world without it.



## MY BLOND WIG

By Theresa Julian

*Theresa Julian is a business/technical writer who lives with her husband, Jim, and four children in Mendham, NJ. She has a daughter in college and 12-year-old triplets (yes, triplets!). Her favorite things to do are spend time with her children, watch a good movie, and enjoy a day at the beach.*

I was diagnosed with breast cancer on October 22, 2007. There are a lot of different things I could tell you about what happened after that day. I could tell you about the shock that gripped me. I could tell you about the tears in my parents' eyes. I could tell you about the fear on the faces of our four children when we told them that their mother had cancer.

But chances are, if you're reading this you've already experienced a great sadness in your own life and don't need anymore. Instead, I'd rather tell you about my blond wig.

Since my teen year I've always taken care of my hair. In high school I would get up early, wash my hair, blow it dry, curl it, spray it, admire it in the mirror ... and then run to the bus stop. Who cared if I was late, my hair looked great. As an adult, I kept up the same regimen: a solid 20 minutes each morning of washing, drying, curling, and spraying. But it was worth it; I walked through the day with the poise and confidence that only someone with great hair can do.

Now, fast forward to earlier this year when my oncologist told me that the

treatment he was recommending would make my hair — my precious hair — fall out. "All of it?" I asked sheepishly.

"Most of it. Maybe all of it," he answered.

Most of it? All of it? What's the difference? What are you going to do with half a head of hair? That's how the most dreaded shopping saga of my life began. I visited many boutiques and tried on hundreds of wigs. Most of the wigs were OK, and some were better than others. But I couldn't find IT. I couldn't find the perfect wig, the one that would let me move seamlessly through chemo without changing how I looked, how others saw me, and most of all, how I felt about myself. The last thing in the world I wanted to look like was a cancer victim.

As I continued to shop, the clock ticked on. Then came the day when I had to make a decision because my hair was falling out in clumps. So I did what I told myself I wouldn't do, I settled. I came home with a mousy brown, conservative wig that was pretty close to my natural hair. It was a safe choice. I wore it without complaint for about seven months.

As if cancer weren't enough, financial hardship also struck our family this year. Once chemo was over, I found myself dusting off my resume and scheduling job interviews. But when I looked in the mirror, I decided that I couldn't go on an interview looking the way I did. After seven months of continual wear, the wig was getting matted, frizzy, and fuzzy, and my own hair hadn't grown back enough.

That was it. I refused to go on a job interview in a fuzzy wig. I began searching for a second wig. But this search was different. This time my search wasn't crippled by fear. I had gotten over the dread of walking into my children's school wearing a wig. I had gotten over the trepidation of going out to lunch with my friends wearing a wig. I had gotten over the awkwardness of people who looked at me crossed-eyed and said, "You changed your hairstyle." Surviving those uncomfortable situations only made me stronger. I had settled for the type of wig I thought I should get, but now I was going to buy the type of wig I wanted to get.

I searched the Internet for hours and finally found just what I wanted: a wig

■ *Continued from page 6*

that was golden in color, soft, wispy and beautiful. I was so excited I had it sent overnight. When it arrived I put it on, styled it, and looked in the mirror.

When I saw my reflection I felt a tremendous wave of release. This was the closest I'd come to looking like my old self in a long time. I felt like I was looking at an old friend whom I hadn't seen in ages, one whom I missed dearly.

I was happy to wear my new wig to a job interview a few days later. When I was waiting for the woman who would interview me, I was thinking about a thousand different things, such as my

resume, my sweaty palms, and my tight shoes, and I had forgotten about the wig. That is until she approached me and said, "I didn't know you were a beautiful blond. Nice to meet you."

I didn't hear much after that. Beautiful blond? No one has ever called me that before. I guess the wig was blonder than I had thought. The woman rushed me into a room and introduced me to several other people. As they were talking, I thought, No one here knows what I've gone through this past year. No one knows about the multiple surgeries, the lymph node involvement, the months of chemo, the scores of side

effects, the tears, the sorrow, the crippling fear. They're just looking at me and seeing . . . a beautiful blond?

That's when I decided that's what I wanted to be — a beautiful blond. The days of being a cancer victim were over. The mousy brown wig was in the garbage. I sat back in my chair and relaxed. For the rest of the interview I let the blond wig do the talking. This was a new me. I looked close to my old self, but somehow better. On the inside I was better too; better than I had ever been. I was stronger, reenergized, more focused, and tremendously thankful for every day of life.



## Survivors Share:



### What color best describes your cancer?

Crimson takes on different hues depending on its medium. As with watercolors its transparency becomes denser as layers are applied. With oils and acrylics it can be thick, and thinned with water or turpentine. Semiprecious stones vary depending on thicknesses and substances much like the aspects of hematology...

— *Kari, diagnosed in 2005 at age 47*

White. The white of doctor coats, hospital beds.

— *Nancy, diagnosed with non-Hodgkin lymphoma at age 42*

Gray — foggy, lingering.

— *Dawn, diagnosed with stage IIA Hodgkin lymphoma at age 39*

Definitely red because of my seemingly constant blood withdrawals in the hospital and the adriamycin that burned a three-inch hole in my chest.

— *David, diagnosed with Hodgkin lymphoma at age 35*

### What food helped you deal with treatment?

You won't find this in any cancer info article... pizza! It was more of a psychological help than anything else.

— *Gunter, diagnosed with stage IIB Hodgkin lymphoma at age 24*

A "cocktail" I invented: Valerie's Magic No-Puke Juice.

#### Ingredients:

Fresh ginger  
Seltzer  
Pomegranate juice  
Ginger juice



#### To Make:

Chop fresh ginger. Place in boiling water for 10 minutes or so. Strain and cool ginger juice. Discard chopped ginger. Fill a glass halfway with seltzer. Add a shot of pomegranate juice (enough to sweeten and add some color) and a shot of ginger juice (or more, depending on nausea level). Add ice and stir. Serve in a fancy glass to feel fancy or a regular one just to get it down.

— *Valerie*

Please visit [www.mskcc.org/bridges](http://www.mskcc.org/bridges) to share your responses to our survivorship survey.

# 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  
Cancer Center

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

*Patient Editor*  
Eileen F. Gould

*Advisory Committee*  
Duane Bailey-Castro  
Jennifer Ford, PhD  
Judith Kelman  
Mary McCabe, RN, MA  
Meghan Newcomer, MPA  
Robin Rawlins-Duell, NP  
Michael Stubblefield, MD  
Page Tolbert, LCSW  
Roseann Tucci, NP

*Cover Bridge Photo*  
Duane Bailey-Castro

*Design & Photography*  
Media Services

If you are interested in  
submitting your story, please  
visit [www.mskcc.org/bridges](http://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](http://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.