

Bridges

Connecting Cancer Survivors



The Story of My Lucky Cubs Hat

By Abby Wood

My twin sister and I were born Chicago Cubs fans, thanks to my granddad and dad. I remember my first trip to Wrigley Field, my first Cubs hat, and the first time we successfully got a baseball from the bullpen. However, it was in the spring of 2008 that my relationship with the Cubs went from one of a typical fan to one that was personal.

In March of that year, I was told that I had cancer: stage IV Hodgkin lymphoma. I was 21 at the time, a junior at Princeton University. I immediately started an intensive, six-cycle chemotherapy regimen with pediatrics at Memorial Sloan Kettering. My family temporarily left Chicago and got an apartment on East 65th Street. New York became the city in which we lived; MSK became home.

While showering after chemotherapy one night, I screamed as half of my hair was suddenly lying in my hand. My sister ran in to comfort me, and the next day my mom took me to a wig specialist. I chose one long wig and one ponytail, both real human hair, both reminiscent of my natural strawberry blonde. Yet, being in a wig made me feel very unnatural, and they spent the majority of the time in my closet.

The only thing that felt comfortable was my old Cubs hat. From then on, my “lucky hat” never left my side. It wasn’t just my Cubs hat that helped me get through my cancer battle. In between rounds of chemo, I took G-CSF, a medication to jump-start my immune system, which caused immense bone pain. One night around 2 AM when



the pain set in, my mom started flipping through the TV channels, trying to find ways to comfort me. I suddenly told her to stop. SportsCenter was on, and they were covering the Cubs highlights. As I listened, I forgot about

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Memorial Sloan Kettering
Cancer Center

Interested in sharing your story?

Please visit www.mskcc.org/bridges



Editorial

By Eileen F. Gould

As spring arrives so does the start of baseball season. The author of this issue's cover story explains how her love for baseball got her through the darkest hours of her treatment. Last fall, her favorite team, the Chicago Cubs, won the World Series for the first time in 108 years!

One of the potential late effects of some chemotherapy drugs is hearing loss, so also in this issue, a young-adult patient explains how state-of-the-art technology has changed her life with the invention of amazing new hearing aids. A Memorial Sloan Kettering audiologist broadens the conversation further, highlighting what resources are available to patients who have experienced this side effect of their treatment and what options they can consider.

Spring always brings thoughts of hope and new beginnings.

Where Are They Now?

I will always be thankful for my Memorial Sloan Kettering doctor and his wonderful nurse; they took good care of me over the years while I was being treated for stage IV oral cancer, and I am now thrilled to be in the head and neck survivorship clinic. Throughout my cancer journey at MSK, there were also several programs that helped me get where I am today, including Art Expressions, where I was able to recapture my artistic skills; the Visible Ink writing program, through which one of my stories was acted out and performed by the professional singers of Broadway's *Motown*; and this very newsletter, *Bridges*, which has published my stories and has always been a comfort to read. I also participate in my Seniors 966 Jazz Club in Brooklyn — I go every Friday night to dance for laughter, to benefit from fellowship, and to listen to music. I also enjoy creative cooking, reading, and being surrounded by caring and loving people. I am truly blessed.

— Ann Colander



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 Wendy Bonilla at 212-639-5007 or patient2patient@mskcc.org.

ASK THE PROFESSIONAL

Treatment-Related Hearing Loss

How can cancer treatments affect hearing?

Some cancer treatments, such as certain chemotherapies, antibiotics, and diuretics, as well as radiation therapy to the head and neck, can affect the hearing. There are three types of hearing loss associated with treatment. The first occurs when the sound coming in from the outer ear is disrupted as it passes through the middle ear. It is most commonly caused by too much earwax and fluid, though it can occur after radiation to the head and neck. This type of hearing loss can be corrected.

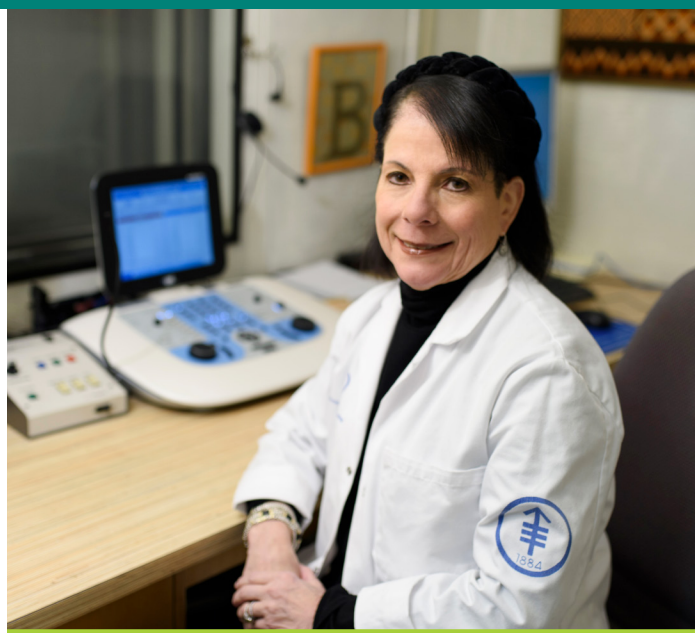
The second type occurs as a result of damage to certain structures that affect hearing, including the cochlea, the eighth cranial nerve, or the cochlea nuclei. It may be due to age or made worse by noise exposure. However, specific medications used in cancer treatment can damage the hair cells in the inner ear, resulting in permanent hearing loss. Finally, mixed hearing loss is a combination of the other two conditions.

Who is most at risk?

People receiving high total doses of the chemotherapy drugs cisplatin and carboplatin are especially vulnerable to hearing loss, particularly younger children. The degree of hearing loss can be influenced by noise exposure, radiation to the brain, genetic predisposition, and interactions with other medications.

What signs or symptoms should patients be aware of?

The most common symptoms are high-frequency hearing loss, ringing or buzzing (tinnitus), and clogging of the ears. Hearing loss caused by chemotherapy drugs is generally in both ears. Tinnitus can subside with time, although exposure to noise without ear protection can make it worse.



Amy Budnick is an audiologist at Memorial Sloan Kettering. She specializes in monitoring for hearing loss that can result from some cancer treatments and has more than 30 years of experience in this field.

If patients are diagnosed with hearing loss or are experiencing tinnitus, what should they do?

Make an appointment with your doctor to discuss some effective ways to cope, including:

- Reducing background and ambient noise when possible
- Concentrating on visual cues, gestures, facial expressions and body movements
- Seeking out restaurants with bright lighting and reduced noise levels
- Avoiding seating near a noise source such as a hallway door
- Considering speech reading training, which teaches you how to distinguish between sounds that look similar on the lips

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Faith Against All Odds

By Nancy Fahmi

Juliet Girgis is a cancer survivor to say the least. She battled cancer for nearly 30 years and beat it in the end. She was first diagnosed with breast cancer in 1988 at the age of 45. At that time, she underwent bilateral lumpectomies, chemotherapy, and radiation — all while raising two children of her own and caring for her niece, who had lost her mother and father years earlier. The cancer could not stop her from being a mother to everyone who needed her. She kept working, commuting from New Jersey to New York City, going to MSK for her chemotherapy and radiation treatments during her lunch hour, then making the one-hour trip back home every evening. The breast cancer went into remission for eight years. At the age of 53, Juliet was diagnosed with breast cancer recurrence (in situ). She required a bilateral mastectomy. By then, she had become a mother-in-law and grandmother. She once again beat that cancer, continuing

to work in New York City and never giving up on helping other women who were facing the same situation. She was always a source of comfort and support to members of her church congregation who had been diagnosed with cancer. She dedicated time to hospital and in-home visits to check up on those going through cancer treatment.

Several years later, Juliet was diagnosed with a cancerous thyroid nodule, which required surgery to remove the tumor as well as a portion of her tongue. The surgery made it difficult to eat or speak, but she quickly overcame this obstacle, never backing down in her strong faith, service to others, and belief that she would be cured.

In 2005, Juliet needed surgery to repair a heart valve, then two years later, she was diagnosed with primary adenocarcinoma of the gallbladder, which had invaded

the liver and part of her colon. She underwent major surgery once again, as well as chemotherapy and radiation treatment, still taking care of her family, which had grown to include five grandchildren.

Presently, Juliet is in remission from cancer, beating it once and for all and demonstrating the true meaning of a cancer survivor. She continues to be treated for her heart condition, but she has not let any of this stop her from being an active member of her church. Once she retired, Juliet joined a group of women from her church who provide services to the elderly in the community, including visiting private homes, senior centers, and hospitals when someone is ill. The group is also active in organizing events and trips for seniors, bringing joy to many who are otherwise homebound.

Throughout her 30-year battle with cancer, Juliet has provided guidance to so many friends, relatives, and fellow church members who have faced their own battles with cancer. She never allowed cancer to prevent her from giving her children and family love and support, despite what she was going through. She is a fighter and survivor of cancer and someone to whom many people look for courage and strength.



At 74, Juliet Girgis is an inspiring example of a cancer survivor, fighting multiple types of cancer for the past 30 years. Through her strong faith in God and the care and support of her husband, family, and Memorial Sloan Kettering, she beat cancer once and for all. Her children, Dr. Wahid Girgis and Nancy Fahmi, both residing nearby in Freehold, New Jersey, have followed in her footsteps as active members in the church community where Juliet has been a source of encouragement to many.



Listen Up!

By Raeanna Gutkowski

Raeanna Gutkowski was a 20-year-old volleyball player and student at Marist College in Poughkeepsie, New York, when she was diagnosed with osteosarcoma. She currently works in the oncology field as a pharmaceutical account manager. For fun, she enjoys reading and teaching cycling classes in Hoboken, New Jersey.

For the fourth year in a row, the audiologist asked me how my high-frequency hearing loss was affecting my quality of life. My answer had always been, “I’m fine. I cope with it.”

But this time, my audiologist suggested a free trial period with hearing aids to see if they made a difference. What did I have to lose?

In 2009, as a college sophomore, I was diagnosed with osteosarcoma. My treatment included cisplatin, a type of chemotherapy that sometimes causes hearing loss or ringing in the ears. Before each round of cisplatin, I underwent hearing tests to measure the degree of hearing loss since the last treatment. Over the course of several months, my ability to hear high-frequency sounds decreased.

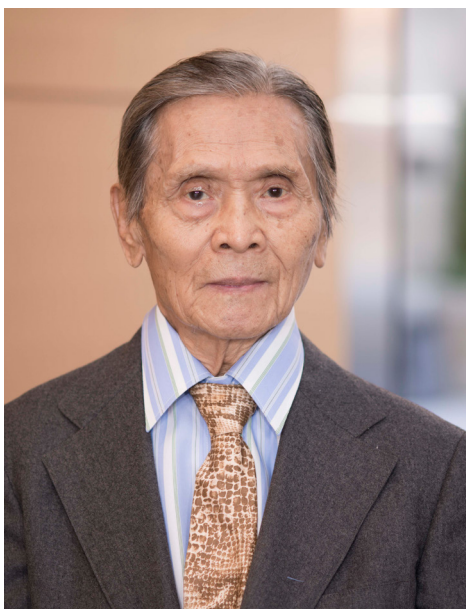
The years went by, and I was invested in my career and life as a woman in her mid-twenties. I thought I wasn’t letting my past health experiences hold me back, but I basically ignored my hearing loss. But the hearing loss was causing problems. I used subtitles when watching TV and had trouble keeping up with conversations in loud settings. The phrases “Sorry?” or “What did they say?” were my most frequent questions. Whispers were nearly impossible to understand, and I relied heavily on lipreading.

My audiologist informed me that if a person’s brain doesn’t hear certain frequencies for a long period of time, it can impact speech because the ears and brain communicate to process sounds, then replicate them for speech. Untreated hearing loss can also have a lasting impact on relationships. It can become as stressful for friends and loved ones as it is for the person with the hearing loss.

I realized that if I did not address the issues now, in 20 years I could be facing true consequences. Osteosarcoma does not define my life, but it will continue to shape it.

After a two-week trial period with the hearing aids, I was sold. I didn’t have to concentrate as hard to keep up with conversations, and my own speaking voice became quieter because I could accurately hear my volume. The audiologist set up the aids to help with just the frequencies I have difficulty hearing. They don’t change the sounds I can hear normally.

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Miracles

By Philip Ng

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.

Philip Ng was born in China but went to college in California, eventually becoming a medical technologist. Since his cancer diagnosis, his faith in God has guided him, and he hopes his own story can inspire others. He enjoys reading, dancing, and seeing movies.

I was diagnosed with liver cancer in 1989. At the time, my doctor told me I had about six months to live, maybe 12 months with surgery. I went ahead with the surgery to remove the tumor, but it soon metastasized, appearing in my left lung. At that point, my doctor suggested not planning any additional procedures; perhaps I could live one more year.

I was so weak that I could hardly walk. I had lost so much weight that I looked like a skeleton. I coughed on a regular basis and frequently suffered from high fevers. Even if I could live one more year, what would my quality of life be?

In desperation, I went to a church to pray. Soon afterward, my doctor called to tell me that my left lung had to be removed and that my glands had tested positive. I didn't fully understand what that meant, but no chemotherapy or radiation was administered. I was lonely, fragile, in pain, short of breath, and facing an unknown outcome. Still, I tried to be positive. I trusted in God. I prayed for mercy and begged for more time.

Twenty-seven years later, I am still here. I believe it helps to remain hopeful, and by having faith, you may heal. This may sound childish and naive, but mysterious things happen. God does answer prayers. Cancer was

a profound experience that taught me to fully appreciate and enjoy life. Since my diagnosis, I have traveled extensively. I also exercise, dance, and read a lot. I try to make right my past wrongs, and I think more about forgiveness, gratitude, and love. I believe that surviving cancer gave me a new beginning in life. As written in 2 Corinthians 5:17: "Therefore if any man be in Christ, he is a new creature: Old things are passed away; behold, all things are become new."

Two books have been particularly meaningful for me as I think about my health experiences and my faith. Anita Moorjani, author of *Dying to Be Me*, had lymphoma throughout her body when she went into a coma. But when she awoke, her tumors had drastically shrunk, and she was

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ultimately deemed cancer-free. Neurosurgeon Eben Alexander III, author of *Proof of Heaven*, had meningitis that severely damaged his cortex. He also lapsed into a coma. When he awoke, he was cured. He recounts meeting his departed sister while in heaven, and she told him there was nothing to fear. Both Anita and Eben believe that they had experiences in heaven and that God loves each of us. Although their stories are different from my own, I strongly share their faith in God and am comforted by their words.

God is merciful and loves unconditionally. Though I am full of sin, God answered my prayers.

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the pain. From that moment on, whenever a Cubs game or Sports Center was on, I focused on the bats of Alfonso Soriano, Derrek Lee, and Aramis Ramirez. I started my mornings by walking slowly on a treadmill while watching SportsCenter. I would crawl into bed when I got home from MSK and turn on the Cubs games, letting the announcers' voices lull me to sleep. All the while, my lucky hat was on my head.

I finished treatment on August 24, 2008, but because of late effects from the chemo, I needed to have hip surgery in 2013 and a left hip replacement in 2014. My Cubs hat came to both operations.

In 2012, Anthony Rizzo joined the Cubs, then in 2014, Jon Lester. I soon discovered that both Rizzo and Lester were lymphoma survivors, and Rizzo had Hodgkin's, like me. My team now had two lymphoma survivors. I started to believe in a victory: This lymphoma connection was too unique and my team too good. It was my time; it was our time.

The 2016 season started with a bang. It was also the first year in a while that I didn't have an impending hospital stay. I was finally, both literally and figuratively, back on my feet. And the Cubs were back on theirs, led by Lester and Rizzo. Everyone knows what happened next: The Cubs had the best record in baseball and came back from a 3-1 deficit to defeat the Indians in Game 7, becoming World Series Champions for the first time since 1908. I cried for my family, and I cried for the cancer community. Here was a baseball team that hadn't won the World Series in 108 years, and it did so on the backs of two lymphoma survivors — unreal.

If ever given the chance, I would tell any member of the Cubs organization all of this. But in the meantime, I am so thankful: thankful for the brilliance of MSK and its Pediatric Day Hospital; the amazing care of Dr. T and Dr. H; the most loving family and friends; and for my Cubbies. Not only did they finally achieve a World Series victory in 2016 but they helped me through my darkest days — and I will continue to wear my lucky hat for the rest of my long, healthy life.



Abby Wood lives in New York City, where she works in marketing for a technology company. In addition to the Chicago Cubs, Abby's other passions include her family, animals, travel, fly-fishing, and good wine. She hopes to one day use her love for writing to share her story and properly thank those who have helped her throughout the past eight years.

Rising Voices is a lively singing group open to MSK patients, caregivers, and survivors. Available at our Manhattan and Westchester locations, Rising Voices is a free and supportive program sponsored by Integrative Medicine and Volunteer Resources. To join, please call 646-888-0800.

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Patients with tinnitus might consider additional tactics:

- Carrying earplugs to use in noisy environments, which can make tinnitus worse
- Using a low-level white-noise fan or radio at bedtime
- Seeking out tinnitus retraining therapy

What options are available following a diagnosis of hearing loss?

Hearing aids come in a variety of styles, sizes, and price ranges. They make sounds louder and are specifically tailored to an individual's hearing loss. An audiologist can discuss options based on your hearing levels and what your lifestyle is like. Assistive listening devices are not personalized but do help in specific contexts, such as listening to the television or in classrooms and meetings. Many public institutions offer these devices at no cost. Alerting devices use vibrations and flashing lights to help with notifications for alarms, doorbells, and telephones.

What resources are available at MSK?

The Speech, Hearing and Rehabilitation Program offers complete hearing assessments and works with patients to find the right course of treatment or strategies



Raeanna shows her hearing aids.

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The hearing aids are also virtually invisible. When I asked my friends if they noticed my “new accessory,” they frequently complimented my earrings. The only visible part is a small clear wire that loops over my ear. Even more appealing are the tech abilities. My particular aids are Bluetooth compatible, and I can stream music or take phone calls just as if they were wireless headphones. I also have an app on my phone that allows me to check the battery life and change the volume based on my environment.

Within a week I couldn’t even tell the aids were in my ears. I am so happy that I finally admitted to myself that my hearing was affecting my quality of life. It’s not a sign of weakness or vulnerability from my cancer treatment because I proactively made a change. I am fortunate to have overcome osteosarcoma and live a happy, healthy life. I want to be able to enjoy that life to the fullest with the ability to hear.

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Memorial Sloan Kettering Blood Donor Program

Help MSK patients by donating blood or platelets to the MSK Blood Donor Program. Both general and directed donations are welcome. Please call for hours and more information.

MSK Blood Donor Room
Schwartz Building Lobby
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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.



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