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Bridges

Connecting Cancer Survivors

Ask the Survivor:
Nick Medley

Co-author Ellen J. Greenfield

What is it like to be both an employee of MSK and a cancer survivor who was treated here?

I've been working at Memorial Sloan Kettering for 14 years and I'm certain that it's no accident. I believe I was put here for a purpose: to help support people through a difficult period in their lives and to give them hope.

My previous job had been in the investment banking industry, and when that job suddenly ended, I wondered what I would do. In fact, I'd barely returned home on that last day of work when a former office manager at the firm called all the way from London to check on how I was doing. Because she knew someone at MSK, she suggested I call them, although she had no idea what their needs were. The job they offered me — door attendant — may have paid somewhat less than what I had been making, but I knew as soon as I arrived here that this was where I was meant to be.

I'm a spiritual man and I believe that things happen for a reason. Now I'm a Concierge at the 53rd Street facility — we're a source for all the information people need to navigate their journey through treatment. We're the first people patients see here, and the last. I try to be an inspiration to them, as they are to me. I offer them information, but more than that, I offer them love, motivation, and encouragement.

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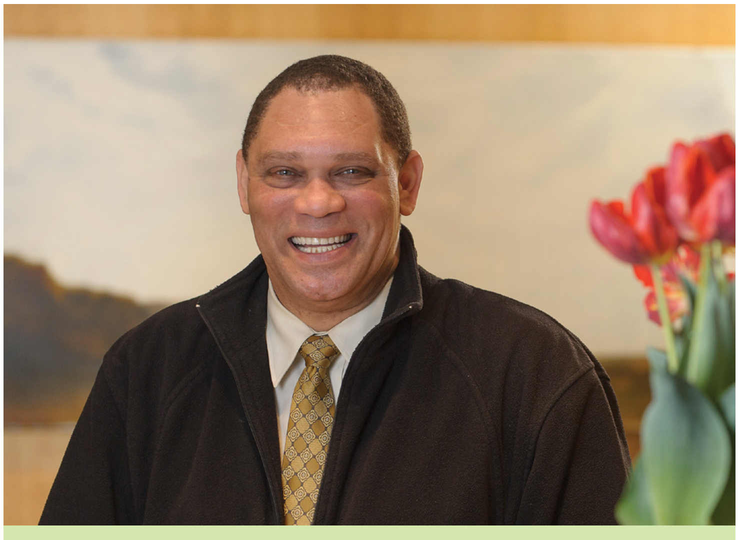
Memorial Sloan Kettering
Cancer Center



An MSK employee for the past 14 years, Nick Medley is currently a Guest Service Representative Lead at our 53rd Street clinic location. Nick was born and raised in Maryland and Washington, D.C., and now lives on Manhattan's Upper East Side; he first moved to the city in 1985 to attend the Academy of Theater and Musical Arts on a full scholarship and has lived in the city he loves ever since.

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

In This Issue

Editorial

By Eileen F. Gould

This issue of *Bridges: Connecting Cancer Survivors* celebrates the sixth year of publication of the newsletter. We have featured more than 100 patient stories and a multitude of articles from MSK's experts and clinicians on a variety of topics affecting cancer survivors, such as late effects and ways to improve their quality of life.

According to a recent report from the American Society of Clinical Oncology, two-thirds of Americans now live at least five years after a cancer diagnosis — a number that was half as much in the 1970s. As a result, patients need improved survivorship care as they will be at risk for conditions such as cardiovascular disease, diabetes, osteoporosis, and secondary cancers.

Cancer survivorship continues to evolve as its own specialty in the World of Cancer. We are so fortunate that MSK is at the forefront of survivorship research and patient care.

Blessing For My Stem Cells

By Arleen Kaplan

Arleen is a grandmother of four whose interests include poetry, music, English mystery novels, volunteering, and traveling (including summer classes at Oxford). She is a licensed social worker and a Penn graduate, having returned in her 40s to earn her MSW. She strongly believes in the power of the mind-body-spirit connection and signs her correspondence, "Keep Celebrating Life!"

On this sacred day of my "new birthing"

I offer these blessings as the infusion of my stem cells is about to begin...

Blessings for the scientists, researchers, physicians whose diligent work has been devoted to sustaining life and finding cures. And the patients who have participated in clinical trials, making this procedure possible.

Blessings to all the hospital staff for the knowledge, empathy, and genuine kindness they bring to our care, who tend to both our bodies and our spirits, who sustain and ease us during this special time of restoration and renewal.

Blessings for the miraculous homecoming passage of my retrieved stem cells, returning today to their bone marrow home to reside there as they grow healthy and strong. Now, as I welcome you back, and join you in this journey of re-birthing and healing, my whole being, body and soul, is filled with gratitude and awe for your wondrous gift of life.

Ask the Professional:

Hair Loss and Thinning in Survivors

By Mario E. Lacouture, MD, Dermatologist

I completed my chemotherapy treatment years ago but my hair has never fully grown back. Why?

Hair loss or thinning, referred to as alopecia, is a well-known side effect of anticancer treatments and can cause significant frustration and anxiety. Although most people regrow a full head of hair after their treatment, it is impossible to predict what will be the case for each individual. Persistent alopecia more commonly occurs in people whose treatment included busulfan or taxanes (paclitaxel or docetaxel), prior radiation therapy, or a stem cell transplant.

Should I see a dermatologist?

A dermatologic consultation may identify other contributing factors to thinning hair, such as inflammation, infections, or hormones. Your doctor may also request a blood test to determine deficiencies in vitamins or hormones. These conditions may be treatable with topical or oral medications. To find a dermatologist near you, visit the American Academy of Dermatology's website at www.aad.org/find-a-derm.

For your appointment, bring as much information as you can regarding your cancer treatment. Photographing your head either at your visit or shortly after is recommended for comparison at future visits.

I am currently on a long-term hormonal treatment. Is it making my hair thin?

Hormonal treatments such as tamoxifen, anastrozole, exemestane, letrozole, and octreotide may cause hair thinning in 10 to 30 percent of people. Since these medications are usually taken for years, the ongoing hair thinning can be distressing. There is no way to predict who will develop alopecia or whether changing to a different medication will end it. An evaluation by a dermatologist is recommended to rule out other causes and to determine whether topical or oral medications may be tried.

What are the topical medications that can help stimulate hair growth?

Clinical studies have shown minoxidil (2 or 5 percent) will stimulate hair growth in most people. Minoxidil is available as a liquid or a foam and is usually applied on the scalp twice daily. For very thin eyelashes, application of bimatoprost (Latisse) on the upper eyelid has been shown to double the length and thickness of the eyelashes, even in people receiving chemotherapy.

Minoxidil is available over the counter, whereas bimatoprost is prescription only. Mild skin irritation at the site of application is the main side effect of these medications. Rarely, bimatoprost has been associated with dark spots in the round, colored area of the eye (iris). Most patients use these products for at least three to six months and are then able to either decrease their use or stop using them altogether, as their hair or eyelashes have been "stimulated" into growing.

What about oral medications?

Finasteride is the only medication approved for thin hair. It is approved for men, but studies have shown that higher doses are also effective in women. Spironolactone, used as a diuretic (water pill), is another medication that stimulates

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Riding High into the Future

By Francis 'Bud' Sanzone

Bud recently retired after 56 years at a family-owned beverage business. He resides in West Palm Beach, Florida, with his wife and has a passion for intrepid travel.

Halloween 2004:

The doctor is all business, unsmiling, staring at my chart. "You have stage 4 colon cancer that has metastasized to the liver and lung."

Cancer. This insidious disease has one singular purpose: to reproduce, take over, and destroy.

He goes on, "You have maybe four to six months to live."

"I am not going to die," I tell him.

It may have been Halloween, but I do not fear monsters. I knew that my best chance was to find a cancer center where there was a clinical trial and a skilled, dedicated physician who'd be willing to accept my case.

Enter Memorial Sloan Kettering Cancer Center and Dr. K.

After seven months of chemotherapy to shrink the tumor, I was scheduled for surgery to remove two-thirds of my liver and a foot of my colon. During those seven months, I denied being sick and refused to let cancer control me. I was very tired at times but I never missed work and ate a full breakfast each morning before I went for chemo.

I prayed as though everything depended on God and lived as though everything depended on me (with help from the "angels" at MSK). I also laughed, which was, as it's often said, good medicine. When someone said, "Nice to see you, Bud," I replied, "Nice to be seen." I still say that.

The surgery was successful and all was well. I remained on chemo for a few more months. The following spring, my scan showed a new site: cancer again. The monster had returned. Chemo resumed but was not working. My surgeon told me to go home and enjoy Christmas because it would probably be the family's most memorable one and my last. He felt that surgery was not an option because there's always more there than shows up on the scan. I explained that I was not going to go home and die. I would rather die on the table trying than just give up, go home, and wait.

I said, "Operate. If I don't make it, I promise I won't tell anybody that I talked you into it."

He was reluctant at first and I knew I needed help. I went to my advocate, Dr. K. Soon, she was back with good news.

"Yes," she said, "he will operate."

After the surgery, the surgeon proclaimed a success, "I'm rewriting the book. I got it all. It had not spread!"

Halloween 2013:

I just returned from my checkup, where I received a clean bill of health. The monster never got me. I owe much to God, my MSK doctors, and my family. They supported me all the way.

I enjoy each day, embrace new adventures, and challenge the future. I'm proud to report that I went from the end of my rope to enjoying zipline rides across Honduras. I'm alive, well, and riding high.

The Unexpected Gift

By Florence Yagoda Sofer

Florence is a 48-year-old mother of one who lives with her 15-year-old daughter in Chappaqua, New York. She is director of global marketing in financial services and an avid reader, Bikram yoga devotee, and cook. She was diagnosed with stage 3b anal cancer in October 2010, underwent three months of chemo and radiation, and is now almost three years cancer free.

Three years ago, my cancer diagnosis made me realize the fragility of life — not just mine but every life. I have watched close friends lose their battle with cancer and watched others fight as I have. No matter how much time passes since my diagnosis, each cancer story hits a chord deep inside me and highlights how close a cancer patient skips along the line of life and death. Grief is a very different emotion when you can feel death creeping outside your own door as it knocks on someone else's. It is deeper and more gut-wrenching knowing this could have been me. Cancer is elusive and sneaky, which makes the uncertainty of what comes next so terrifying. But I have learned that life goes on.

This disease has forced me to reassess my life in ways I never dreamed. And yes, forced — cancer is a dictator; there is no democracy along this journey. But as a result of having cancer, my friendships are now deeper and how and who I love more meaningful. Time spent with my daughter is a gift and I cherish every moment that I can hold her hand and watch her grow. I appreciate the beauty of nature — its colors, sounds, and vibrancy. I view every change of season as a miracle and a sign that I am here and participating in life.

My spiritual life has grown in directions I never imagined possible but embrace with awe and self-realization. I am more mindful about life after death and understanding what God means to me. I stop more often to breathe deeply and put life in perspective. I don't sweat the small stuff as much as I used to. If I am running late, so be it — I will ultimately always reach my destination. I am committed to paying it forward — I truly believe karma is a powerful concept. I now have a bucket list and I work toward accomplishing new things every day. If I have a whim, I listen to it carefully as I understand the importance of living for today, not tomorrow. I have decided that negativity will not rain on my parade — it is my parade and I choose the songs to play, even if cancer is sometimes the chorus. I truly believe it's not what is on the outside of a person that counts but what is on the inside that is meaningful. From cancer treatment I learned appearances do not define me. There is no room for vanity when you have cancer.

From my cancer journey, I have an understanding of how pettiness, anger, and hate are negative emotions that create unwanted, bad energy and affect your health. While I can't control cancer, I can control my approach and reaction to it. Eat well, live well, and be happy is now my daily mantra. I must embrace all cancer has taught me with complete acceptance or else I would go mad trying to change cancer's path.

Cancer, as horrific as the reality of the disease is, has a silver lining. It makes me laugh louder, keep those I love closer, feel my emotions more deeply, and appreciate the life I am destined to live. I have a new understanding and clarity about my purpose in life and know with complete conviction, thanks to this unplanned journey that my soul is more fulfilled and I am now prepared for wherever life takes me. Cancer has been my ultimate epiphany and, oddly, my blessing.

Where Are They Now?

In 2009, 5-year-old Klaus was diagnosed with a rare soft tissue sarcoma in his lower left jaw called plexiform fibrohistiocytic tumor. Extensive surgery was required to remove his jaw, teeth, nerves, and tissue, which was followed by years of reconstructive surgery. Leap forward five years and Klaus is getting ready for sixth grade middle school with a beautiful smile. He's active in sports, speaks at public events, and has been learning to play the clarinet this year. Considering all the oral work completed, his music is testimony to the professional gifts his surgeons, oncologists, and care providers have devoted over the years.

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hair growth in women. Both are available through prescription and must be discussed with your oncologist before taking them.

I just want to hide my scalp and make my hair appear thicker. Do you have recommendations?

Besides wigs, extensions, and other partial head covers, there are powders (diCesare Thicken Hair Builder, Toppik Hair Building Fibers, proTHIK) and sprays (Top Coverage for Bald Spot and Thinning Hair, DermMatch Topical Shading, Bumble and Bumble Hair Powder, Fullmore Hair Thickening Spray) which, without stimulating hair growth, create an appearance of thicker, fuller hair. Many of these products are available online.

Can I still dye my hair if it is thin, or if I lost it during chemotherapy?

Yes, but you should wait about four months after treatment in order to have enough hair to color. It is safe to use hair dyes available at most salons, but some people who are concerned about the effects of chemical dyes prefer to use henna-based products instead, which are also recommended by the American Cancer Society.

Are there any shampoos that work to stimulate hair growth?

No. There is no evidence that a ny shampoo will stimulate hair growth, even those that are advertised to do so. Save your money and see a dermatologist, who can recommend other types of products that really work.

What about laser combs and hair transplants?

Studies have indicated that certain light-emitting devices (HairMax laser comb, LaserCap, Capillus) may stimulate hair growth in men and women who have the type of hair loss that occurs with age. These devices have not been tested in cancer patients or survivors, and their use is controversial.

Hair transplants can be very effective and natural-looking if done by a certified trained professional (www.iahrs.org/hair-transplant/) but require that some hair be present on the scalp to be transferred from one part to the other. These methods can be expensive and should be used only after other treatments have failed.

In Sickness and in Health

By Renate Vecchione

Renate is a 48-year-old single mom of a 24-year-old son. She will be graduating from Queens College with degrees in anthropology and elementary education. After being diagnosed in April 2011 and undergoing eight rounds of chemotherapy and a stem cell transplant in December 2011 for mantle cell lymphoma, she is currently disease free. She is thankful to her family and friends for their support.

The hot morning of April 20, 2011, was made even hotter by the 103-degree fever raging inside of me. I was sick again. However, this time my neck swelled up to ten times its normal size and throbbed with pain. I took a dose of Nyquil and hoped I'd be good as new.

After sleeping through the day, I awoke in a puddle of sweat. I had to take care of my 84-year-old father, who had had a stroke. I feebly crawled out of bed wondering why the Nyquil didn't work. I assured myself that the illness would be gone in the morning, but during the night, my fever went up to 104 degrees and would not break. I needed medical care but was too weak to walk. My then 22-year-old son carried me off to the doctor. The ten minutes I sat in the waiting room seemed like ten hours.

My doctor immediately sent me to the hospital. I do not remember what happened next. I woke up five days later in the ICU with a severe case of sepsis and a 107-degree fever. The medical team wasn't sure that I would pull through. As if that weren't bad enough, I was paid a visit by the oncology team. The infectious disease team felt my enlarged lymph nodes needed to be biopsied. I simply couldn't fathom that I had cancer. Impossible. I scoffed at this notion.

My faith that I was improving grew stronger when I was moved from the ICU to a regular room. On a concoction of antibiotics, I remained in the hospital until the cancer biopsy results came in. On what I hoped was my last day there, the rain was beating on the hospital windows and I desperately wanted to go home. My anxiety took over and I demanded to be released. Little did I know this was only the beginning of my numerous hospital stays. The clock was ticking — half past ten — and no one had come to share any information. When I saw the director of oncology sit at the end of my bed, I knew she would be delivering bad news.

She conveyed my diagnosis of mantle cell lymphoma. When I arrived home, I raced to the computer. I never thought I would see the word "terminal" by this diagnosis. How could my life end so abruptly? My father, who was an employee of Memorial Sloan Kettering Cancer Center for 50 years as a foreman of the instrument shop, begged me to seek their help.

I was seen at MSK within three weeks. My medical plan would include four rounds of outpatient chemotherapy, and three as an inpatient, followed up with an autologous stem cell transplant. With each passing treatment I was thankful for a fighting chance.

After what seemed like an endless roller coaster of sickness and self pity, the day came to be admitted for my transplant. This treatment would be my saving grace. My only thought as I became sicker each day was that this too would pass. I wouldn't be 85 pounds forever.

Today, I tip the scales at 122 pounds and I have been disease free for almost a year and a half. Since the transplant wiped out all previous immunizations, I received six of my childhood shots. It has been an uphill battle, but I was fortunate to have superb doctors and patient volunteers who shared their stories and their strength and helped me through the roughest of patches. I look forward to the day when I can return the favor.

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About ten years ago, I was having difficulty swallowing because of a lump in my throat. I went to my primary doctor and a specialist, but they said it would improve with time. I came back to work and a nurse greeted me and asked about my "vacation." When I told her it was not a vacation but a health issue, she looked at me and arranged for me to be seen by the head and neck service almost immediately. It turned out I had not only a goiter but also the early stages of thyroid cancer. In fact, the lump was so large that the doctor wondered why I hadn't choked in my sleep. It was such a blessing that I was here. I became a survivor because of that nurse and because MSK saved my life. If I hadn't been working here, I probably wouldn't be around to tell the story.

I am, at heart, a positive person. I try to instill that in the people I meet. I try to let them know that it was possible for me to get through hard times, and it is possible for them, too. Not just because I went through an illness, but because I know in my heart that this is the truth. I feel blessed and thankful to be here to do that work.

What do you do to relax?

One of my favorite things to do is photography. I've had a passion for it since I was a kid. It nourishes and revives my spirit. It puts my mind in a different element, where I can see the beauty of life and the Earth and creation. I especially love nature and images of reflection that remind me of all the connections in life. A photographer friend of mine saw my work and encouraged me. Again, I was blessed to find the right place at the right time when I discovered The Creative Center, where people dealing with illness are invited to take arts classes and workshops. Photography has become part of my healing and now I'm almost never without my camera. In 2013 and 2014 my photos were chosen to be part of a calendar sponsored by Novartis, the pharmaceutical company.

One thing I know: Tomorrow is not promised to any of us. We have to make the most of each day and how we spend our time. What you put into life is what you're going to get back is the way I see it. I try to be aware of the moment and stay thankful. That's really what it's all about.

Nick was recently featured on ABCNews with Diane Sawyer.
You can view the video here: goo.gl/zb3ND1.

Memorial Sloan Kettering
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Patient Editor
Eileen F. Gould

Managing Editor
Katie Decker, MA

Cover Bridge Photo
Duane Bailey-Castro

Design and Photography
Medical Graphics and Photography

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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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