

From the Editor

By Eileen F. Gould



This summer 2022 issue of Bridges is our 57th issue and the start of the 15th year of publication. We are delighted that this newsletter for and about cancer survivors continues apace. The "War on Cancer," launched by President

Richard Nixon in 1971, just turned 50. The goal was to win the "war," but many survivors prefer different metaphors, since cancer and its late effects can last a lifetime.

Survivorship is an integral part of cancer care, and thankfully, the number of cancer survivors continues to grow. As of 2019, there are approximately 16.9 million cancer survivors in the United States, which is 5% of the population.

The month of June is recognized nationally as Cancer Survivor Month in the "world of cancer." It's an important time to acknowledge the difficulty cancer survivors continue to face and the support and care they need — and it's a time we here at Bridges like to honor and recognize.

Survivors of cancer often face serious and persistent adverse outcomes, including physical, emotional, and psychosocial challenges, because of their disease and treatment. As we all know, family, friends, and caregivers are also impacted. Many people think that once you finish treatment, that's it and your life is back to normal. However, often that is not the reality. Memorial Sloan Kettering Cancer Center continues to be a trailblazer in cancer survivorship, offering many post-treatment programs and support for both patients and caregivers. Take a look at this issue of *Bridges* to read personal contributions from members of the MSK and survivorship community.

If you would like to share your story or receive an email copy of *Bridges*, please visit www.mskcc.org/bridges. *Bridges* is now printed on recycled paper and, as always, is available online.

MSK Blood Donor Program

More than 1.6 million people were diagnosed with cancer last year. Many of them will need blood and platelet transfusions, sometimes daily, during their chemotherapy treatment. More than 53,000 blood products are transfused to patients at Memorial Sloan Kettering Cancer Center each year. Many cancer treatments would not be possible without the availability of blood products. There is no substitute for human blood, so we rely on the public to help maintain an adequate supply for our cancer patients.

Currently, there is a national blood shortage due to the COVID-19 pandemic. As more individuals test positive for the virus, less people are eligible or willing to donate. There is no risk of getting coronavirus from the donation process, and extra precautions are being taken to protect our donors and staff. Donors are screened for COVID-19 exposure when making an appointment, all donors and staff are required to wear a face covering, and continuous sanitization is performed.

The blood and platelet collections we receive from donors help maintain an adequate supply of blood products in times of blood product shortages. Donating blood and platelets truly does save lives. If you are between the ages of 17 and 75 and meet eligibility requirements, you can donate blood every 56 days. Platelet donations can

be made weekly. People aged 16 may donate blood with parental consent; donors over the age of 75 can donate with a physician's written consent. Family members and friends of patients are invited to participate in our directed donation program: Blood and platelet donations can be directed to a specific patient if the donor and patient blood types match.

The MSK Donor Room is open every day, except Saturday. The hours are Sunday, Monday, and Friday: 8:30 a.m. to 3 p.m.; Tuesday and Wednesday: 8:30 a.m. to 5 p.m.; and Thursday: 8:30 a.m. to 7 p.m. It is in the lobby of the Arnold and Marie Schwartz Cancer Research Building at 1250 First Avenue, and we offer five hours of free donor parking.

How to Make an Appointment for Donation or Find Out More Information

It's important that you make an appointment to donate as the Donor Room can only accommodate a limited number of donors in a single day. Please be flexible when scheduling your donation!

- Find information and schedule online: www.mskcc.org/giving/blood
- Call the Blood Donor Room: 212-639-7648
- Email the Blood Donor Room: donateblood@mskcc.org

You Think Dating Is Hard? Try Dating with a Disability

By Sylvia Hyra

was diagnosed with osteosarcoma at the age of 12. And let me tell you, it wasn't something I expected. I was on the swim team, and while I was swimming breaststroke, it felt like my bone was popping out of my leg. It was something I couldn't explain. A few weeks later, I eventually went to the doctor because a bump formed on my leg and I knew something was wrong. After seeing a couple of doctors, the diagnosis was finally made. I went through treatment and surgery and, eventually, into remission. I have been in remission for almost 20 years now!

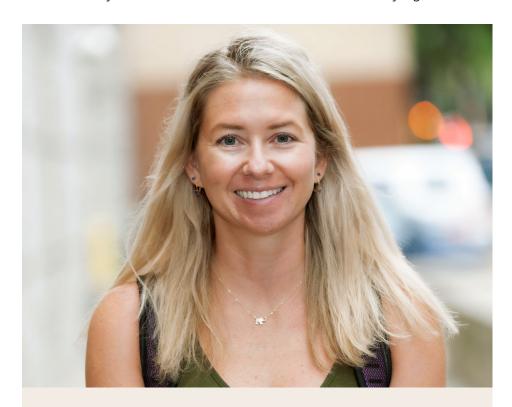
Going through treatment and surgery was not easy. After having a bunch of complications and going through more than one surgery, at the age of 14 I decided to amputate my leg. I knew it was the right thing to do and it would give me a better lifestyle from where I stood before the amputation, but there was one thing I didn't think about — dating.

Dating in 2021 is difficult as is, with all the dating apps and stuff and everything about looks. Now imagine dating with a disability. It was very hard for me from the beginning. I never knew if I should disclose the information about my leg on the first

date or third date, or when it was a good time to disclose. When I first started dating, I never mentioned anything about my disability and never put pictures of myself where my prosthesis was visible in dating profiles. Because of my disability, I didn't think any guy would want me or swipe right on me. I felt discouraged. Part of this may have been because when I was in college, I hid my disability — a lot of people talked and stared, especially the guys, and it was just very hard to hear them talking about the girl with one leg. Throughout the four years of college, I knew I wasn't myself. After I graduated, I decided to seek some help and went to therapy. Therapy was the best decision I made.

My therapist helped me overcome my fear of walking around in shorts and helped me become who I once was before my disability. I didn't care anymore that I had one leg. I cared that I was healthy and able to do anything I wanted.

This helped me change my outlook on my dating life. I posted pictures of myself with my prosthesis visible in dating profiles. I disclosed my disability on the first date, and if the guy didn't accept my disability, he was not the one for me. I went on many dates - some dates seemed to not care, and some I just knew had a problem with this. Today, I am happily dating someone who never cared from the moment we met. He looks at me and sees me for me. He does not just see a disability. So, if you're struggling, just hang in there. Your perfect person will come along!



My name is **Sylvia**, and I am a cancer survivor. The number one thing I love doing is traveling — just tell me when, and I'll make sure I'm there! My dog Boris is my best friend and almost travels with me everywhere. A quote I like to live by is "People living deeply have no fear of death."

Keep Going

By Ramón de la Cruz

had my very first colonoscopy on September 29, 2017. I agree this isn't a very exciting achievement or conversation, but I'll keep going. The doctor informed me I had stage 3 colon cancer. I was by myself and didn't know enough about the diagnosis, so I wasn't overly concerned. Being a true realist, I was just determined to overcome another one of life's obstacles and keep going. Later, in August 2020, the actor Chadwick Boseman died, and I learned he had received a similar diagnosis to mine. This situation was a biggie, as I later realized.

At the time of my diagnosis — and as the youngest of three siblings, single, and living in Fort Lee, New Jersey, minutes from my parents' home — I assumed responsibility of coordinating my parents' 24/7 caregiving at their home as they approached their golden years. For sure, there were added time demands and stress involved: however, I felt tremendous gratitude for their perseverance and story. My parents left their home country as political exiles, leaving behind everything they've ever cherished, to start anew in the U.S. with three very young children. I was unquestionably determined to keep going and ensure they would never be placed in a home.

A month later, I underwent a successful six-hour robotic surgery and eagerly walked out of Memorial Sloan Kettering Cancer Center three days later. The medical advancements in this field of surgery are incredible, and I have no visible scars, except for a small chest scar from a Mediport* implant. My surgeon and medical team were excellent and motivated me to keep going, despite the realization of losing all core muscle strength and diminished lung

capacity. My fitness exercise history helped me enormously through the intense surgery and recovery. The six months of chemotherapy that followed was, however, a different story - causing weight loss and depleting my endurance and enthusiasm. I received permission to self-remove the biweekly medicine canister from my implanted Mediport, so I didn't have to travel to New York City and have it removed. Ironically, while recovering, I stayed at my parents' home for an invaluable six months before returning to fulltime work. My parents passed the following year within 40 days of each other, after having been married more than 60 years.

The chemotherapy left me with peripheral neuropathy (PN), which basically leaves you experiencing numbness and an annoying tingling sensation in your fingers, legs, and feet. My oncologist, who has been an important supporter, emphasized the importance of exercising to eliminate these symptoms and to deter any relapse. My old exercise routines like running, weight training, and bicycling – didn't motivate me anymore, and neither did the idea of rejoining a fitness club. I struggled but felt compelled to keep searching for a new fitness training practice and improve my health without delay.

I was familiar with vinyasa yoga, having practiced it in between weight training days — but vinyasa was an "easy 'n' nice" form of exercise. So naturally, I did the opposite of vinyasa and joined a hot yoga (aka Bikram yoga) studio, located minutes from my home in Fort Lee. Despite not really knowing what I was getting into, I sensed intensely that this was the training I required to improve my health.

Here's what I encountered: an exercise room heated to 105°F with 40 percent humidity and a yoga routine consisting of 26 minutes, plus two breathing exercises lasting 90 minutes! My first class felt like being in the first grade: totally lost, without the right uniform on, and longing to leave quietly, if only I just could. The experience thoroughly knocked my senses. In the beginning, I needed several days to recover before forcing myself to take another class. I was hardly flexible, lacked any core strength, and struggled to breathe. The PN in my feet left me so offbalance, I frequently stumbled — with arms and legs flailing - appearing like a sweat-soaked collapsing windmill.

I figured I'd just finish my introductory month, but then something magical happened. The PN diminished significantly, and I learned a lot by focusing on disciplined practitioners in class. Then my yoga postures began to improve gradually. I also recovered faster, breathed easier, felt stronger, and eventually worked my way to taking up to six training classes in a week. I've gained an appreciation of how special the yoga community is and how conducive yoga practice is to one's overall well-being. It doesn't matter your yoga practice level, your age, or if you suffer physical challenges. Commit yourself and keep going: While you'll encounter all kinds of life challenges that converge to derail your efforts, just embrace being able to practice the best way you can on any given day.

As of November 1, 2021, I am four years cancer-free and have been practicing hot yoga for more than three years. I'm unquestionably committed to a lifetime of yoga practice. Hot yoga





Saving Boobs, One Fun-Filled Post at a Time!

By Suzette Simon

In early January 2020,
I was diagnosed with
breast cancer in my right
breast. I had a bilateral
mastectomy in June 2020.
By the end of that year,
I got new boobs and a new
look (due to chemo and
radiation), and found a new
purpose and passion after
learning that Black women
with breast cancer have a
40% higher mortality rate
than white women.

Yes, that's an alarming stat, and it's just one on a long list of breast cancer disparities. I'm now an advocate on breast health, and I've been producing humor-filled health awareness PSAs that not only target communities of color but also speak to all women, since 1 in 8 women in the U.S. will be diagnosed with breast cancer.

I advocate via a platform I created. It has an incredibly silly name, but cancer is hard to talk about and people love to laugh. If others have forged a path to success with their comedy characters, I'm hoping for the same in order to make an impact and save lives! We don't like to talk about cancer, but we love to laugh.

I now consider myself the self-appointed Master of Cancer Badassery, in the running to become America's Next Top Cancer Survivor (LOL!). My mom lost her life to breast cancer 30 years ago because she had no insurance. She was left dying in her final moments on a hospital gurney in the crowded hallway of a public hospital. I walked away briefly, and upon my return, someone had stolen her wig (which, at that point, was more like a matted Chewbacca toupee) ... Sadly, it seems that people are really, really desperate for weaves in Brooklyn. So when I think of what my mom endured and the health statistics among the Black community, I take pride in being a #CancerBadass!

Since my mom died of recurring breast cancer five years after her surgery and my hormone-blocking medication is a five-year deal, I'm concerned. So that's the time frame I'm working with on my breast cancer journey. Although life's priorities have realigned, laughter is still the most relevant part of healing myself and healing those around me.

Now it's one year down and my ta-tas are toddlers! My boobs have been through a lot, but they've come out of it like champs. They're still filled with expanders, which makes the metal in them a helpful spot for kitchen magnets and my daily to-do list. They're the GOATs! You know, the Greatest Of All Tiddles. Before cancer, my five-year plan was to simply renew my lease. Now, it's important to be a catalyst for change and use the time I have left to have a positive impact on the world.

So every day, I wake up and I want my boobs to change the world, I want my boobs to beat breast cancer, and I want my boobs to find a boyfriend. Sadly, the biggest challenge of them all has been that bovfriend — but I'm certain my boobs and their agenda will be iconic! My plan as a #CancerBadass is to shake things up and change outcomes. I wanna be your Black breast friend! I look forward to dominating boobs, cancer, and the whole world (in a good way, of course!), one fun-filled post at a time.



Ask the Professional

Radiation Fibrosis Syndrome

By Franchesca König, MD, and Jillian Hobson PT, DPT

What is radiation fibrosis syndrome?

Radiation fibrosis syndrome (RFS) may occur as a late complication of treatment with radiation therapy. While the goal of radiation therapy is to treat cancerous cells, treatment may also affect healthy surrounding structures, including skin, soft tissue, muscle, and nerves, among others. This can lead to progressive tissue fibrosis and sclerosis, which essentially is the abnormal hardening, thickening, and scarring of body tissue. While this condition may occur acutely during or shortly after treatment, it usually occurs months to even years after exposure to radiation. It typically is a lifelong disorder that, depending on the severity, can have negative long-term functional and quality-of-life complications.

What are common signs of radiation fibrosis syndrome?

RFS may present in several different ways, depending on the structures being affected by irradiation. Regarding the neuromuscular system, it can manifest as skin tightening, weakness due to muscle atrophy, joint contractures (as a result of stiffness of muscles, tendons, and skin), nerve (or neuropathic) pain, and painful muscle spasms. Other structures may also be affected, for example, lymphedema may occur if lymph nodes are affected, and there may be blood pressure variability if the vascular system is affected. For example, in some patients with head and neck cancers treated with radiation, conditions such as trismus (inability to fully open the jaw) and dropped head syndrome (inability to keep the head up due to severe weakness of the muscles of the back of the neck) may occur. Trismus can in turn limit oral hygiene and food intake, while dropped head syndrome may cause significant posture issues and pain.

How is radiation fibrosis syndrome diagnosed?

RFS is typically a clinical diagnosis - meaning your physician or healthcare provider will diagnose this condition based on the symptoms you are experiencing and a thorough physical examination. While not always

necessary, imaging such as MRIs may help visualize fibrotic changes of muscles and tendons. Nerve tests, known as electrodiagnostic studies, may help determine if (and how severely) nerves may be affected.

What is the physical therapy treatment for radiation fibrosis syndrome?

Individuals who develop RFS after treatment often benefit from skilled physical therapy. At the first physical therapy session, also known as the initial evaluation, the physical therapist (PT) will ask you several questions about how your radiation-induced fibrosis is affecting your quality of life. During the initial evaluation, the PT will also assess how your radiation-induced fibrosis is negatively interfering with soft-tissue mobility, muscle flexibility, joint range of motion, muscle strength, and posture. Based on your evaluation, the PT will establish an individualized treatment plan. The physical therapy treatment plan for radiation-induced fibrosis commonly consists of manual therapy, a multicomponent exercise program, and a home exercise program.

Manual therapy is a clinical approach where the PT utilizes hands-on techniques to address restrictions in the fascia and/or muscle that may be contributing to pain, tightness, or loss of joint range of motion. Examples of manual therapy techniques utilized to address limitations related to radiation-induced fibrosis include myofascial release and soft-tissue mobilization. When performing myofascial release, the PT applies sustained gentle pressure to loosen and stretch the fascia. When carrying out soft-tissue mobilization, the PT utilizes a variety of strokes and pressures to restore muscle flexibility.

The multicomponent exercise program that is typically prescribed to individuals with radiation-induced fibrosis includes stretching activities, muscle-strengthening exercises, and functional training. Equipment commonly used in physical therapy are weights, resistance bands, stability balls, bicycles, and treadmills. Whether you are new to exercise or are a seasoned athlete, the PT will guide you in making sure that you are maintaining proper posture and body mechanics. Additionally, the PT will determine how long, often, and at what intensity you should perform the prescribed exercises.



Throughout the physical therapy plan of care, the PT will also design a home exercise program. The home exercise program is an individualized set of therapeutic exercises that a patient is taught by the PT to be completed at home. The home exercise program is important since it reinforces what was taught during physical therapy sessions and maximizes potential for improvements in physical function and recovery.

What additional treatments are available for radiation fibrosis syndrome?

Other types of interventions may also help, depending on the area that is affected. For example, postural bracing may help for dropped head syndrome. Injections, such as botulinum toxin, may be beneficial for trismus and certain types of neck pain related to radiation fibrosis for head and neck cancers. From a medication standpoint, there is currently no standard of care treatment for RFS, however, certain medications, such as vitamin E, vasodilators, and cholesterol-lowering medications have been explored.

Franchesca König (right) is a physician who specializes in physiatry with a subspecialty in cancer rehabilitation. She completed her fellowship at Memorial Sloan Kettering in 2019 and upon graduation has stayed on board with the Rehabilitation Medicine service, where she sees patients along the continuum of their cancer care, focusing on both function and quality of life.

Jillian Hobson (left) is a Senior Physical Therapist in the outpatient rehabilitation therapy service who joined Memorial Sloan Kettering Cancer Center in 2014. She is board certified in Geriatrics by the American Board of Physical Therapy Specialists and is currently located at the David H. Koch Center for Cancer Care at MSK.

The Gift of Life. Filled With Gratitude.

By Arlene M. Karole, CHCP

So here I was, at 49 ... who would have thought that instead of planning for my 50th birthday, I'd be planning for a mastectomy of my right breast? Really!

Something Doesn't Feel Right

It was after two mammograms and an ultrasound. I had a pinprick-like feeling (literally like someone taking a pin and pricking my skin with it) in my right breast. Thus, my doctor ran a few extra tests, but shared, "Everything's normal." I persisted that something's not right, and my doctor ordered an MRI. Afterward, my doctor's office called and said, "Your MRI lit up," and I needed further testing.

And so, it was two months before my 50th birthday. The following two breast needle biopsies went on to confirm the large extent of the DCIS (ductal carcinoma in situ), but missed the invasive cancer. With that, I was headed into surgery for a mastectomy of my right breast.

Life Changes for the Best

Today, I am thriving and doing great more than six years later. My annual medical care at Memorial Sloan Kettering Cancer Center is exceptional, and I'm comforted that I'm in the best of hands. Breast cancer, I have come to find all these years later, is a lifelong journey. And while my diagnosis was devastating, if I had the chance to go back and change my diagnosis, I would not change a thing.

Hearing "You have cancer" is jarring but helped me change my life for the better. I reevaluated and changed my diet, exercise regimen, and lifestyle choices, focusing more on health and wellness every day. Whether eating better foods, doing yoga or mediation, or biking, I've researched and found many excellent resources, including books, videos, blogs, and podcasts that have supported the new positive changes I have made

in survivorship. A driven type A New Yorker, and a self-professed multitasking wizard, I try to stay in the present moment, to just *be* in the now and not stress.

It does take effort to change patterns learned over a lifetime, but with focus and a desire to change, I have found we can do anything we choose to and create anew.

I am now an advocate and share my experiences to help others with their initial diagnosis as well as in survivorship. My volunteer work helps keep me up-to-date and knowledgeable, and I am humbled to be able to serve and help others through my personal experiences. I came to learn breast cancer does not discriminate by gender, age, race, borders, celebrity, or how high you have climbed on the corporate ladder.

I coined a "breast friend" as those who helped and supported me during and after my diagnosis. That very summer after my mastectomy, I got to pay it forward and become a breast friend to someone else. I never realized men get breast cancer too, until my first breast friend was, in fact, a male.

Early on, I took an active stance in owning my diagnosis. I took a lot of notes from my doctors' appointments, journaled, and researched new words that were thrust at me. After collating it all (including three surgeries and a tattoo of an areola), my notes unexpectedly turned into a book, and I have become a published author to help others!

Lessons Learned Along the Journey

In New York we have a saying: "If you see something, say something." And

as a breast cancer survivor, I share: "If you feel something is not right, do not let it go." Be persistent! Listen to your body. And go to the doctor. I always say, "Own your diagnosis, and don't let it own you." To anyone fearful of doctors, I say, "Wouldn't you rather go and find out it's nothing or catch it early on?"

Try to find peace and be in the moment. There's nothing like a cancer diagnosis or a global pandemic to help us look inward and reprioritize in life what is truly important. I'm blessed to enjoy and love my work as a director in an incredible health system; I have a wonderful community of family, friends, and colleagues; and I've learned to find joy in each and every day. And for my good health and the ability to help others on their lifelong journeys — I am filled with gratitude.



Arlene Karole is a certified healthcare CPD professional (CHCP), educator, and published author. She is active with national breast cancer organizations and is an advocate for both those just diagnosed and in survivorship. She holds a master's degree in health services administration.



In July 2020, I was diagnosed with triple-negative breast cancer. Throughout the weeks following my diagnosis, well-meaning friends, family, and acquaintances offered an abundance of guidance, while I privately wept and yearned for the restoration of normalcy. Starting treatments seemed like a top priority, and the doctors at my local hospital were ready to go — but a chorus of my bossy loved ones chanted, "MSK, MSK!" While booking face-to-face meetings with Memorial Sloan Kettering Cancer Center's world-renowned oncologists required a painful delay, I'm glad I waited! I didn't realize how much time we would spend together or how much my respect for my team would grow, but their collective kindness, responsiveness, and straightforward scientific approaches assured me that I was in the right place.

MSK West Harrison — an invaluable source of serenity over the past year — has provided a surprisingly peaceful counterpoint to seemingly endless cancer treatments.

As a middle school art teacher, a professional artist, and the founder of a global children's art nonprofit, I hadn't enjoyed a full night's sleep since 2013. Building strength for chemotherapy, surgeries, and radiation forced a significant change in my practices and rhythms. At first, the endless wait times at MSK bothered me. But my frustration didn't change the outcome, so I started to settle into a routine that I eventually learned to love. At MSK, I'm guiltlessly out of touch with the outside world. I have used the time to be unproductive, a previously unrealized value. While at MSK, I think, sleep, breathe, zone out, and play *Words With Friends* on my phone. In the absence of productivity, I have regained balance.

The hospital is filled with people of all shapes, sizes, genders, and ethnicities who generally keep to themselves but who form a diverse and bonded community. Lifesaving doctors and accomplished clinicians are the benchmarks of the MSK brand. They are heroes who deserve the spotlight, but there are so many more heroes and reasons to recommend the hospital. Upbeat receptionists and smiling guards set visitors' minds at ease. Supportive nurses who refrain from judgment offer useful tips on how to address the plethora of side effects that accompany each stage of cancer treatment. An ever-present cleaning crew assures immunocompromised patients that the space is sterile and safe. Unending wait times may unnerve newcomers, but the delays are caused by doctors giving each patient ample attention or by growing numbers of patients waiting for long and unavoidable treatments. I view my time spent at MSK as a welcome chance to decompress and slow down.

If you're just starting the cancer treatment process, try to surround yourself with those who love you most. Let them care for you. Staying positive and levelheaded is helpful for getting through treatments, but false positivity can be toxic — and it's often not at all possible. Allow yourself to feel and deal with your genuine emotions. Over the past year, I have experienced lows and some highs, anaphylaxis, severe pain, nausea, energy loss, diminished mental acuity, and an array of additional side effects. Cancer therapy wasn't on my bucket list, and I hope never to do it again, but my world has benefited from the time to slow down and from knowing each of the wonderful people who make MSK a haven for those of us who are in need of healing.



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wrote "Adjusting" for the fall 2012 issue of Bridges, describing my first three years post-bone marrow transplant. Nine years later, I am still following my own advice: "Live life every day." There have been little bumps in the road that require attention to diet and lifestyle. I live in Northern New Jersey with a woman I met shortly after the article was published. She is "Oma" to my two grandchildren, and I am "Grandpa" to her three grandboys. We have gone bicycle riding in Germany, the Netherlands, and the Czech Republic. I continue to paint landscapes and write. The Visible Ink Company, along with David Hyde Pierce, performed my story "Time"

at their live readings. I learned to play the guitar. Cancer was a good teacher. COVID-19 health protocols have not been bothersome. I continue do volunteer work at MSK. I give talks from the patient's perspective for new employees. As a patientto-patient volunteer, I have had the opportunity to help patients on their transplant journey. Every one of those conversations has been a gift to myself as I remember when I was beginning my journey. And now, I can share the joy that comes with each "re-birthday." From time to time, I meet someone who does not know about my survivorship. They say, "It's good to see you." And I always think, "It is good to be seen."

Joining the Be The Match®

registry through the National Marrow Donor Program® (NMDP) means volunteering to be listed as a potential blood or bone marrow stem cell donor and being ready to donate to any patient in need of a transplant. To learn more about joining the registry, visit www.bethematch.org or call 800-MARROW-2 (800-627-7692).

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