

#### From the Editor

By Eileen F. Gould



It is hard to believe that we have been living through this global pandemic for an entire year. A year ago, most of us thought our lives might be impacted for maybe a month or two. Never in our wildest dreams did we think we would be wearing masks, social distancing, and living in fear of an invisible villain that would follow us everywhere.

For cancer survivors, living with the fear of recurrence has its own set of challenges during COVID-19. All the familiar feelings of fear and anxiety are heightened by the "what-ifs" in

The World of Cancer and during the pandemic. Many patients are fearful of keeping up with their annual screenings due to the risk of exposure. MSK encourages everyone to follow up with their clinicians to discuss how to navigate their individual health issues and concerns. Early detection can make a difference as we travel The World of Cancer even during COVID-19.

If you would like to share your story or receive an email copy of *Bridges*, please visit www.mskcc.org/bridges

### **Screening and COVID-19**

By Kristen Cognetti, MSN

In March 2020, the United States was thrust into the COVID-19 pandemic, and shelter-in-place restrictions forced many patients to put medical care and appointments on hold. As restrictions are lifted, and offices are opening and resuming care, it can be difficult for patients to weigh the risk of exposure to COVID-19 against the risk of delaying medical screening and visits.

To ensure safety, the hospital has initiated several screening protocols for patients, staff, and visitors. All employees are required to complete a daily health screening check and wear appropriate personal protective equipment (PPE) depending on the clinical environment they are working in. Patients and visitors are screened for COVID-19 symptoms and travel prior to their visit and upon arrival to the facility. Masks are required at all times. Certain visits and procedures require COVID-19 testing which will be directed by your health care team.

MSK remains open and dedicated to screening and treating cancer for all patients. However, the process and visits may now be somewhat different than in the past. These include new ways of meeting, such as telemedicine visits or utilizing satellite locations, but the quality care that patients are accustomed to remains the same.

The importance and timing of medical visits - including screening, treatments, and procedures - should always be discussed with your medical team. Based on your personal history, your medical team can help guide you about which tests are most important to your health, and which, if any, can be delayed or modified. The health and safety of patients has always been a top priority for MSK and continues to be throughout the current circumstances.

### **Bionic 55**

By Jeff Bryant

Jeff Bryant is 25 years old and from Point Pleasant Beach, New Jersey. Previous to cancer, he was a competitive basketball player with dreams of pursuing a collegiate scholarship. However, cancer would turn his life around, and now he is pursuing a master's degree in Museum Studies at George Washington University in Washington, DC.



In 2014 I was a high school senior in New Jersey, playing competitive basketball on a team that had won several top championships. I loved the sport, and my goal was to go on to prep school and gain a basketball scholarship. But life had other plans for me.

At the end of my senior year I was diagnosed with a rare bone cancer, osteosarcoma, in my left femur and knee. I went through chemotherapy for nine months, had my femur and knee replacement in September, and also had two separate lung surgeries to remove nodules of cancer that had spread there. I was declared cancer-free on St. Patrick's Day 2015.

In fall 2015, I began attending Flagler College in St. Augustine, Florida. However, I was only there for about two months when my entire femur and knee became loose. It was the worst agony of my entire life. I returned home and had a second femur and knee replacement in January of 2016, with a custom-made prosthesis. I returned to Flagler for all of my sophomore year, and then in August of 2017, the screws connected to my hip became loose and I had to have a third surgery, which resulted in me missing that fall semester. I returned to college for the following spring, and then in July of 2018, I had a fourth leg surgery due to the bottom stem of my prosthesis and knee loosening. Still, I managed to return for the school year that year.

I finally finished physical therapy in February of 2019 after four years. These years of extra setbacks that followed cancer treatment were the most challenging time of my life, even more so than treatment. In college, I faced difficulty managing my time between classes, physical therapy, and other activities. As a result, I not only struggled physically, but also academically and socially. I was on academic warning one semester, and I had trouble making new friends because of my leg disability. Despite this, and with the support of my wonderful doctors and nurses at Memorial Sloan Kettering, family, friends, professors, and physical therapists, I managed to overcome these obstacles. By the time I received my bachelor's degree, I had made Dean's List four times.

I can no longer play basketball, but I continue to live life to the best of my abilities. My goal post-college is to attend graduate school and receive a master's degree in museum studies. History has always been my second tremendous passion after basketball, because I grew up reading books and visiting museums. This led me to develop my ambition to one day work with history in the form of preserving objects and setting them up for public displays. I hope to one day become a curator for a history museum and work with collections.

On my four-year cancer-free anniversary this past St. Patrick's Day, I started a blog to raise awareness of bone cancer and give information and tips on how to live with it.

My goal is to help build a community of bone cancer fighters and supporters under a common cause to stop the disease from affecting more lives.

Along with everyone who helped me along this path, I want to thank the cancer organization I am now a part of for giving me splendid opportunities to have fun during my tough stages – like sending me to the basketball Final Four in Indianapolis in 2015 – and allowing me to be part of a second family of people who also know cancer well.

Last but not least, I give my thanks to God for guiding me through these challenging years. All who are mentioned contributed to my ability to stand where I am now and pursue my desired future. I would not have made it through every one of the challenges bone cancer gave me without them.

Editor's note: This story was written with help from Ellen Greenfield, a committee member of Bridges.

#### **Ask the Survivor:**

# **Genetic Counseling and Testing for Hereditary Cancer**

By Ceji Bridges

While the cancer in Ceji's family is hereditary, not all cancer is hereditary. This means that not all cancer runs in families. If you have questions or concerns about your personal or family history of cancer, please speak with your doctor about whether genetic counseling may be useful for you.

### Why did you decide to have genetic testing done?

I was fifteen when my father died of stomach cancer at 33 years old. When he was initially diagnosed, he was told he had nine months to live. Only after surpassing the nine months and making it to a year did he inform me what was happening to him. By that point, he had begun chemotherapy.

Over time, I watched him physically become a different man due to both the cancer and its treatment. Ultimately, he withered away in a hospital bed. A fighter to the end, he survived twice the amount of time the doctors initially gave him.

Twenty years later, my family found out some interesting news.

In late 2019, my paternal grandmother confirmed that stomach cancer indeed runs in our family. My second cousin decided to get genetic testing done after her mom died. Based on her genetic test results, her four children elected to undergo genetic testing, and they tested positive for the CDH1 mutation (the same gene that can cause diffuse gastric cancer or lobular breast cancer in women). Since there is no definitive way to identify the type of stomach cancer associated with CDH1 mutations before it has become invasive, it is often recommended that patients with a CDH1 mutation have a risk-reducing total gastrectomy to prevent cancer.

All four of my cousin's children opted to have this surgery.

I had my annual pap smear, and I told my nurse practitioner about the recent family discovery. Based on this and my father's death, she recommended genetic testing.

### Did your genetic test results influence any decisions in vour treatment?

I gave my saliva sample, merely a swab with the equivalent of a Q-tip end. Less than three weeks later, I was informed that my test came back positive for the same CDH1 mutation that my cousin and her children have, indicating that I was at increased risk for gastric/breast cancer. Based on the test results, my doctors recommended that I go to Memorial Sloan Kettering Cancer Center.

Although the Coronavirus pandemic had greatly impacted MSKCC intake, I was able to set up an appointment and have multiple tests done, including biopsies. Thankfully, everything came back benign.

Despite that, I was given the recommendation to have my stomach removed. I had to make an ultimate life-changing decision. I spent days thinking of how my life would be changed permanently. Remembering what my father had gone through, I chose to be proactive instead of reactive. I had my total gastrectomy on May 4, 2020.



Ceji Bridges is a school librarian at a Pre-K - 5th grade school in Queens, NY. She lives on Long Island. She enjoys having high tea at any place that's posh or dainty and she loves to dance. She's a maniac on the dance floor.

I was inpatient at MSKCC from May 4th - May 12th. On May 18, 2020, the pathology report came back positive for stomach cancer.

## What effect has this had on your day-to-day life in survivorship? Do you have advice for others considering genetic testing?

The effect that this has had on my day-to-day life in survivorship are the short-term effects from the life-changing surgery. From extreme weight loss to esophagus issues, and other physical changes, it's been a day-to-day journey in healing in various ways. My advice for others considering genetic testing is to do your research on all of the possibilities that the results may lead to. Speak thoroughly with your doctors and other health care providers to make the best decision for you and your overall health.

Editor's note: This story was written with help from Ellen Greenfield, a committee member of Bridges.

#### **Ask the Professional:**

## **Genetic Counseling and Testing for Hereditary Cancer**

By Amanda Catchings, MGC, CGC, and Alicia Latham, MD



(Left) Dr. Alicia Latham is a board-certified medical geneticist and family medicine physician who specializes in identifying and caring for people with a genetic susceptibility to cancer. She provides genetic testing, long-term surveillance, and cancer risk-reduction for patients with multiple types of hereditary cancer syndromes.

(Right) Amanda Catchings is a board-certified genetic counselor in the Clinical Genetics Service at MSK. As a genetic counselor, she cares for people with cancer and families who may be at a hereditary risk for cancer. She specializes in genetic counseling for inherited gynecologic and gastrointestinal cancer predisposition syndromes.

### What is genetic counseling and testing for hereditary cancer?

Cancer genetic counseling is the process of assessing and understanding the risks of hereditary cancer for an individual and their family. Genetic testing for hereditary cancer is performed with the goal of identifying alterations, called mutations, in certain genes which may increase a person's risk to develop certain types of cancer.

## How can genetic counseling and testing for hereditary cancer be beneficial to cancer patients and survivors?

Genetic counseling and testing for hereditary cancer can help you better understand how your cancer diagnosis may play a role in the pattern of cancer in your family. Genetic test results

may provide an explanation as to why you developed that cancer and may be used to help guide your treatment plan. Although you may have had a cancer diagnosis in the past, you may be at an increased risk to develop another cancer in the future if you have a genetic mutation, and may be eligible for specialized cancer screening. Identification of a genetic mutation can also prompt family members to pursue genetic testing to determine if they inherited the same genetic mutation and the associated cancer risks. Some people may also choose to use their genetic test results to help with reproductive decision making.

### After I have my genetic test results, what comes next?

Since not all genetic test results are straightforward, you may benefit from

having a discussion with a genetic counselor or other clinician who has expertise in cancer genetics and is able to appropriately interpret your test results in the context of your personal and family history. This should include an individualized risk assessment to help you best understand what your test result means for you and your family, and what cancer screening recommendations may be appropriate. If your genetic testing identifies a mutation, this could help inform you about your future risk to develop cancer and may allow you to take steps to reduce risk or detect cancer at an earlier stage. A genetic counselor can also help identify who in your family is at risk to share the genetic mutation and discuss at what age genetic testing would be appropriate for those relatives.

## What steps should anyone interested in genetic counseling and testing for hereditary cancer at MSK take?

While most cancers and tumors are sporadic - occurring due to chance, environment, or other factors that are not well understood - genetic testing may be warranted in several different scenarios. Some of these scenarios include cancer diagnosis at a young age (e.g., breast or colorectal cancer before age 50), rare cancer diagnosis at any age (e.g., ovary, pancreas), multiple individuals in a family diagnosed with the same or related cancers, one individual with multiple primary cancer diagnoses, or individuals/families who previously underwent genetic testing through a different doctor, hospital, or company with some type of genetic mutation identified.

If you are interested in genetic counseling and testing at MSK, you may ask your MSK physician(s) to refer you to the Clinical Genetics Service (CGS). Alternatively, you may contact the CGS main office directly at 646-888-4050. In order to provide the best care possible, we may ask that you complete a Family History Questionnaire and provide relevant medical records prior to scheduling a consultation.



Elaine (Layne) Sasser is a 70-year-old retired special education teacher and professional actor in Nashville, TN. She is a widow and mother to two wonderful people, and has a completely amazing granddoll (pictured with Elaine above). Without MSKCC, she would not have had the chance to live her best life.

### FROM MSKCC TO NASHVILLE!

By Elaine Sasser

In 1965, I was 15, in 10th grade, and I had a fast-growing, very large tumor in my neck which was wrapped around my carotid artery, windpipe, and larynx. After my surgeon at home closed me up, I was sent to MSKCC where I was diagnosed and treated by my heroes.

After surviving surgery, I was left with no voice (it did come back eventually) and a large tracheotomy. Over the next two years, I had multiple surgeries to close the tracheotomy which succeeded in 1967 as I prepared to graduate from high school.

While at MSKCC, I became interested in medical social work; when I went to college at Hollins, it became my life's intent. I worked as an intern at a local hospital and ended up being assigned to the special education classroom. There, my heart and mind experienced my personal Big Bang! I was a TEACHER!

Since then, I have had the pleasure and honor to spend my adult life

working with people in Nashville of all ages, disabilities, and learning needs. This includes people who were medically and emotionally fragile, who needed early intervention, had behavior disorders, learning disabilities, or were in correctional education. Even though I am retired, I'm in contact with hundreds of my students. What a life rainbow!

Along the way, I met the cutest hippie, and we grew up together and received master's and doctorate degrees (Him!) and were married for 44 years, before he passed away. He was a renowned principal in the school system. We had a wonderful life together, along with our children and large groups of rescue dogs.

You know, great teachers are great performers, and with my family's support, I have also acted in theatre, music videos, feature films, short films, etc. my whole adult life in Nashville. And, it all comes back to the things I learned at MSKCC.

Give and receive love. Care about others. Learn from everything that comes your way. Sometimes, the greatest gifts come in the ugliest packages. Open yourself to others and it will surround you!

In many ways, my time at MSKCC was a wonderful gift. I learned about love and the many ways it was shown and shared. The nurses and doctors were amazing, and made me feel valued as a person. The experience changed me for the better. Because of the hospital, I became different - more caring and loving. The adult that I am was created in your hospital.



### Life is Good

By Tom Gibbons

Tom Gibbons is retired and lives on the Upper West Side with his girlfriend Susan. He splits his time between New York City and his home on Florida's Gulf Coast. He enjoys traveling, biking and spending time with family and friends. He also enjoys frequently playing an admittedly mediocre game of golf.

It was the fall of 2013, and I was about to escape New York City for a few days in the Bahamas with a close friend. I was looking forward to what I felt was a long-overdue break. Little did I know that this trip would ultimately lead to a life-changing and lifesaving experience.

Three days before I left for my trip, I was in the middle of a game of tennis when I suddenly had a shortness of breath. I experienced the same thing while walking up my block to catch my flight, but I really didn't think twice about it. I just wrote it off as being out of shape.

I flew to Florida a few days before my trip to the Bahamas. While in Florida, I noticed that two small cuts on my index fingers appeared to be infected. Strangely, I also developed painful mouth sores. While I dismissed this as nothing serious, I didn't want to deal with seeking medical treatment while on vacation in a foreign country. So, I decided to go to a healthcare clinic at a local pharmacy. The pharmacist suggested that I get my fingers checked out at a local hospital because she had a sense something wasn't right.

After undergoing a routine blood test at the hospital, a doctor walked into my examination room, introduced himself, and in no uncertain terms told me that I wouldn't be going on my trip because I had cancer. I was in a state of disbelief, so my family took charge. They concluded that Memorial Sloan Kettering (MSKCC) was the best cancer center to treat my rare form of leukemia. It was also close to my home, which was key since I would require several months of daily outpatient chemotherapy after I left the hospital.

After a three day stay in the hospital in Florida, I was discharged and per my doctor's advice, I flew back to NYC and went directly to MSKCC. Upon admission, my sister and I met with my doctor, who calmly explained that I had a rare and aggressive form of leukemia called acute promyelocytic leukemia (APL). If not diagnosed and promptly treated upon manifestation of symptoms, patients with APL can quickly develop life-threatening problems. If untreated, the median survival rate is less than one month. While APL was once one of the most lethal types of cancers, it can now be

treated effectively and patients can lead a full life.

The ordeal was very challenging - physically and emotionally – but I had unwavering support from my family.

I also had the best doctor and nurses, who encouraged and motivated me throughout my treatments. My faith is an important part of my life and I made sure that I attended Sunday service in the small chapel at MSK. I relied on my faith to get through it all, and while I had the utmost confidence in my doctor, I needed all the help that I could get, and wanted to hedge my bets!

After seven weeks, I left MSKCC with no traces of cancer, and with no IV pole tagging along. It was beyond liberating and even the NYC air seemed fresh! After a few weeks at home regaining my strength, I began daily outpatient chemotherapy for the next nine months. Thankfully, everything progressed as hoped.

I am forever grateful, and I will never forget the people who were there when I was at my weakest. My girlfriend and my family were by my side every day.

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My good friends visited and called frequently. So now I make sure that I am there to support them when they face serious medical challenges of their own. I want to pay it forward, and pay it back.

I often think about my hospital roommates. My first roommate was several years older than me, and we quickly became friends. He was the first one of us to leave the hospital. Unfortunately, he passed away a few years ago. My second roommate was a musician who was 35 years old, and had been in the hospital for about nine months before we became roommates. Sadly, I was the only one of us who was able to walk out of the hospital, as he passed away one month later.

I realize that my life will never be back to where it was before. But that isn't a bad thing. In fact, there are more positives than one might think to be true. I try to live a healthier lifestyle now and I exercise regularly. I also try to be cognizant of my diet, albeit with limited success. I make it a point to travel more, worry less, and laugh as much as I can.

I find increased enjoyment in the simple things: small acts of kindness, an unexpected "hello, how are you?," phone calls or emails from friends. Smiles and laughter have far more significance. I also try to be there for family and friends when they are faced with difficult times. They were there for me.

It's been almost seven years now, and I am happy to say that my life has returned to normal, or to what has become a "new normal." I remain cancer-free, and continue to see my oncologist three times per year. To say that I am lucky would be the understatement of my lifetime.

The entire ordeal is something that I will obviously never forget. It is in the forefront of my mind at times, and never far from my thoughts. I am often reminded of my experience every time I hear the word "cancer," or read stories of those who develop the disease, or learn about new breakthroughs that will improve the survival of patients, or ideally, offer a potential cure.

I frequently think about my doctor, my nurses, my hospital roommates.

I think about how good life is and how lucky I am.





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