

Spring 2022, Vol. 56

Bridges

Connecting Cancer Survivors



In this Issue

Guest Editorial	2
Cover Story: An Unexpected Miracle	3
Ask the Professional	4
Loving That Journey for Me	5
Tips to Improve Your Financial Health	6
Surviving Cancer Treatment	7



Memorial Sloan Kettering
Cancer Center

Guest Editorial

By Emily Tonorezos, MD, MPH



Emily Tonorezos is a general internist and Director of the Office of Cancer Survivorship in the Division of Cancer Control and Population Sciences at the National Cancer Institute (NCI). In that role, she leads the NCI's efforts to support survivorship research. To learn more, visit survivorship.cancer.gov.

When it was founded more than 25 years ago, the Office of Cancer Survivorship (OCS) in the National Cancer Institute (NCI) represented an achievement for the many survivors, family members, advocates, and providers who had spent years calling for more attention and more research in cancer survivorship. At that time, the National Cancer Act was already 25 years old. But, in the words of Dr. Fitzhugh Mullan, the feeling among survivors was that “despite... success on the treatment front, we have done very little in a concerted and well-planned fashion to investigate and address the problem of survivors. It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and sputter on their own in the belief that we have done all we can.” During a Rose Garden ceremony at the White House, President Clinton announced the formation of the Office of Cancer Survivorship, giving survivorship a research home at the NCI. The mission: to enhance the quality and length of survival of all persons diagnosed with cancer and to prevent, minimize, or manage adverse effects of cancer and its treatment.

Since then, progress in cancer detection, treatment, and supportive care has moved in a rapid and, at times, dramatic fashion. As one recent example, documented growth in the number of non-small cell lung cancer survivors was

attributed to advances in treatment that occurred between 2013 and 2016. We anticipate that by 2030, the number of cancer survivors in the United States will be more than 22 million. NCI research dollars committed to survivorship have also grown dramatically. In 1998 – the first full year of OCS funding as part of the Division of Cancer Control and Population Sciences – survivorship research in the division focused on approximately a dozen broad areas, with 13 grants funded at a total of \$3,150,482. In 2020, the division funded 165 grants, at a total of \$111,581,130, focused on cancer survivorship.¹

As Eileen Gould, *Bridges* Patient Editor, noted in her interview celebrating the 10th anniversary of *Bridges*, “The cancer community is so much more aware of survivors today.”

Yet not all survivors have benefited equally from these successes. Disparities in survivorship outcomes and clinical care continue to be observed. While some barriers, such as provider knowledge, have been documented, others are poorly understood. Many survivors and their families still feel “lost in transition.” Growing populations of survivors, including those living with advanced or metastatic cancer, have been underrepresented in survivorship research. Challenges in finding high-quality primary care, care coordination, cancer-related costs, health behaviors, and lingering or new physical and psychological side effects continue to be significant.

It was with all this historical knowledge and passion that I joined OCS just over a year ago. My goal is to help cancer survivors and providers through the work of the NCI: funding research, creating opportunities for collaboration, and generating resources (like questionnaires) that support investigators. Of course, these tasks are shared by many people and groups at the NCI. At the same time, it was survivors who pushed for the creation of the OCS, and it will always be the survivors who show the way.

¹These grant numbers include funding through our annual appropriations, including resources for implementation of the STAR Act and additional resources provided through legislation such as the 21st Century Cures Act, which authorized funding for the Cancer Moonshot.

An Unexpected Miracle

By Brenda Lucas

March 2019 changed my life forever. The telephone rang. It was my OB-GYN. My heart raced like a high-speed jet zooming through the wall of the sky. As I held the telephone to my ear, I took a deep breath. And then she said, “Brenda, you have been diagnosed with stage 1 breast cancer.” A trio of doubt, fear, and uncertainty seized my soul. Cancer! Time stood still, giving me a few seconds to question myself. *Is this real or a dream?* Her soft words, “Are you OK, Brenda?” pulled me from deep and inner thought. “Yes, I’m trying to process it all,” I responded. Cancer! Was this some kind of karmic payment for a past deed? For years, I served cancer patients with undying love and commitment. I was a good steward of my health, keeping annual checkups and required follow-ups.

Fourteen months prior, I cared for a family member who later passed from cancer. And then, I experienced an epiphany, a spiritual strength, to face two choices, two paths, two proclamations: “Fight and live!” or “Give up and die!” I decided to fight.

I decided to “live” — a faith proclamation rooted in the belief that there is a higher power that orchestrates my life through the good, bad, and the indifferent. The fight began with renewing my faith in God. Faith doesn’t presuppose that you don’t have doubts, fears, setbacks, heartaches, and disappointments. It is a hope in a higher force, a determination to believe for the best, even if things don’t turn out the way you expected.

Second, I trusted my care to the professionals at the Memorial Sloan Kettering Cancer Center. The medical team and staff guided me step-by-step through a web of treatment, procedure, and aftercare. They were kind, helpful, and thoughtful. When I experienced low days, they embraced me and celebrated my high and joyous moments.

My journey to recovery began in April 2019 when I had a lumpectomy followed by eight sessions of chemotherapy. During chemotherapy, I developed neuropathy. Then I was placed into physical and occupational therapy for weeks. In October of that year, I started four weeks of radiation treatments as I experienced the side effects of fatigue and physical weakness. The journey was long and tedious. I had cancer but it didn’t have me! Today, I am cancer-free.

Due to my treatment, I thought that I would never sing again. I started singing as a child in the church and then at social and gala functions. My bout with cancer left me fatigued and voiceless. My mouth would be filled with cold sores and a sore throat, making it very difficult to speak or sing. I listened to music and reflected on my life. When I couldn’t sing an entire melody using my voice, I would stop and then continue singing the melody with the voice in my head. For the first time in my life, I began to understand song as a story — life moments put to music. I had a light bulb moment! Until I fully recovered, I decided to write a song about my journey. I gained a new perspective about the art of music. It became a platform to vent and share my story with others. We all have a story within, a song waiting to be written. When I sing, I think about you, me, and how we can fight and be cancer-free.

I started a platform for a group of six women who will chat and exchange stories through roundtable discussion and reflection. So often, women feel alone, isolated, and fearful. Our endeavor is to keep women privy and connected to relevant information from leading medical and clinical studies that support overall wellness.

Prayer, positive thinking, medical treatment, and the support of family and friends are the recipe for personal wholeness and healing.

Brenda Lucas is a single mother and grandmother living in Brooklyn. Her lifetime goal is to sing, serve, and become a registered nurse. She lives for today and lets tomorrow take care of itself.

Ask the Professional

Young Onset Colorectal Cancer

By Robin Mendelsohn, MD

What is young onset colorectal cancer?

Colorectal cancer (CRC) is cancer that involves the colon (large intestine) and rectum (the last part of the colon). Patients with CRC are considered young onset if they are diagnosed before the age of 50. For many years, 50 was considered the age to begin screening for CRC in the general population (this was recently decreased to 45 — more to come below!). In the United States, we have seen a decrease in the number of people both diagnosed with and dying from CRC. This has mainly been attributed to CRC screening, most notably colonoscopy, which can not only detect CRC early but also prevent cancer by identifying and removing precancerous polyps. In this same time period, we have seen an unsettling increase in the number of people under 50 being diagnosed and dying from CRC.

Why is young onset CRC increasing?

The bottom line is that we just don't know. The majority of these patients do not have a family history of colorectal cancer or a genetic mutation that would predispose them to CRC. The known risk factors associated with CRC — drinking excess alcohol, smoking cigarettes — do not seem to be associated with young onset CRC. There is some suggestion that obesity and diabetes may be risk factors, and this is an area that is being actively researched at MSK and worldwide.

What is the Center for Young Onset Colorectal Cancer at MSK?

The Center for Young Onset Colorectal Cancer was established in March of 2018 and recently expanded to all gastrointestinal cancers. It is the first clinic of its kind in the world dedicated to providing comprehensive patient-centered care to patients diagnosed with CRC under the age of 50. The center is focused on helping patients from diagnosis to survivorship with support services designed for their specific needs, including social work, fertility, sexual health, psychiatry/psychology, nutrition, and integrative medicine.



Robin Mendelsohn is a gastroenterologist who focuses on taking care of gastrointestinal issues in people with cancer. As codirector of the Center for Young Onset Colorectal and Gastrointestinal Cancers, Robin is particularly interested in learning why younger people are developing colorectal cancer and how best to treat them, from screening to diagnosis — and, hopefully, through survivorship.

The center is also conducting research to try to figure out why this increase is happening, as well as to how best take care of these patients.

What are symptoms of CRC?

In its early stages, people may not have any symptoms. The most common symptoms of young onset CRC are blood in the stool, abdominal pain, and change in bowel habits. If you have any of these symptoms that persist, please reach out to your primary care physician or gastroenterologist for further workup.

What should patients and survivors be aware of regarding CRC?

Screening for CRC is now recommended for everybody beginning at age 45. Those at increased risk for CRC (those with a family history of CRC, a genetic syndrome associated with CRC, a history of inflammatory bowel disease, or radiation to the abdomen and pelvis) often start screening earlier. There are also different options for screening, including stool-based tests and colonoscopy. It is so important for people to discuss with their primary care providers when to start screening for CRC and the different options. Screening saves lives!

Loving That Journey for Me

By Tricia Drechsel

March is Colorectal Cancer Awareness Month — a statement I may not have given a second thought to, until last year.

Now, every day is Colorectal Cancer Awareness Month. At 38, on my way to an annual OB-GYN appointment, I told my husband to expect me home soon. At this visit, I first heard the word “mass,” a growth that should not be where it was. It was July 1. I remember dates now, something I never paid much attention to earlier. By July 22, my diagnosis was confirmed, stage 3 colorectal cancer, due to the size of the tumor.

Within the span of a few weeks, I — an active mother of two young children, used to watching my son play baseball and my daughter dance, and overseeing homework and playdates — started hearing words like “staging,” “radiation,” “chemotherapy,” and “colectomy.” It sent my brain and body into crisis mode. I have suffered from ulcerative colitis for almost 18 years and knew my large intestine was never on great terms with me. I just didn’t think it was life-and-death serious ... until it was. I discovered that, living with a chronic illness, one loses perspective of “normal” and “healthy.” I missed signs and ignored symptoms. And, suddenly, stage 3 cancer was my reality. I met with the team at MSK in early August, and a treatment plan was made. I was going to do chemo, radiation with oral chemo, and finish strong with a removal of the colon. But often things don’t go as planned. The port disagreed with me, I developed blood clots, and I needed blood transfusions — and I was not a huge fan of the radiation machine. But I did it. All of it. At the height of the pandemic, I underwent surgery. I was alone (no family allowed), but the incredible MSK team made sure

I had the best care and was sent home in five days. The post-surgery support of the nurses and staff was amazing.

March 25, 2021, marked my one-year post-surgery anniversary. This time the year before (March 2020), I was too sick to be with my students. Now, I’m back to work, following my passion — teaching —

“scanxiety.” I am scared of doctors and sometimes diagnose myself with “eyebrow cancer” if I feel a twinge of pain above my eye. But for any *Schitt’s Creek* fans out there, I have been able to “love that journey for me.” As strange as it sounds, battling cancer made me a better person and gave me a more positive perspective of life. Anyone who has been through



again. I don’t even get mad at the copy machine anymore (most of the time).

Physically, I am seven organs lighter because of the surgeons’ (plural) recommendations of removing some extra organs to keep the chance of recurrence down. Cancer is as much a mental journey as a physical one. I still think of the radiation machine upon hearing the sound of automatic doors, but my love for shopping is back! I am not in pain anymore and have learned to dress keeping my ostomy in mind. I look like the cool mom I always thought I was. I recently turned 40 and, wow, I am grateful to be able to say that. Now I play more, sing and dance more, and whine less. I laugh more and cry less. I don’t take my time for granted. Yes, I still battle

colorectal cancer knows it is not a “month” of awareness; it’s a time to reflect on our strength and the amazing people who helped us through our diagnosis.

Tricia Drechsel has been a special education teacher in Parsippany, New Jersey, for the past 18 years. She lives with her husband, two children, and her not-super-well-behaved dog Buttercup, age 2. She loves to read, do TikTok dances in the kitchen with family members, and watch *Schitt’s Creek*, *Friends*, and *The Office* over and over and over again.

Tips to Improve Your Financial Health

By Melanie Steele, MPH, and Beverly Bertolini

Regardless of where you are in your cancer journey, you've likely been concerned about how you were going to be able to afford your care. Our MSK Patient Access Coordinators (PAC) in Patient Financial Services (PFS) have shared their top 3 tips on ways you can build your financial health.

1. Don't avoid financial conversations. We are here for you. We know that this is overwhelming and returning to whatever your version of normal won't happen the day after your last treatment. Our financial staff have encountered too many patients who have suffered in silence and have avoided having conversations about paying for their care. The anxiety that some patients have really impacts their quality of life. By avoiding these conversations, patients sometimes miss out on programs that were developed to help patients who are having difficulty paying their bills. Everyone's situation is different. Talk to us so that we can provide you with options and create a plan that helps you and your future.

2. Get familiar with your health insurance coverage. We have had countless meetings with patients who aren't aware of what their insurance or prescription plans pay for versus what they don't. If there are gaps in your coverage, or medications that aren't included on your formulary, it's better to know so that your clinical team can provide possible alternatives and MSK's financial staff can look at what financial assistance options can be recommended.

3. Learn the language. It is difficult to understand your health insurance coverage if you don't know the difference between a deductible and a co-pay, or in- and out-of-network coverage. A lot of these terms are not very intuitive, so you are not alone. What is particularly important for cancer survivors, as it relates to understanding insurance terminology, is being able to decipher any insurance plan changes that may limit your access to future cancer care.

Open Enrollment happens every year whether you're covered by an individual policy, your employer, or Medicare – and assuming that your coverage will be the same every year could be a costly mistake. Stay informed about any changes to your existing coverage, both medical and prescription.



Melanie Steele (right) is the Director of Patient Financial Engagement in MSK's Patient Financial Services (PFS). Melanie is a healthcare professional with more than 20 years of experience in the healthcare setting. She possesses a varied and broad range of experience in the areas of administration, communications, hospital billing, and health education.

Beverly Bertolini (Left) is a Senior Patient Access Coordinator in MSK's PFS. Beverly joined MSK in 2014, and she is currently providing financial counseling services to patients at the MSK Westchester location. She also serves as the Program Coordinator for the PFS Financial Literacy Program.

If you're not sure of the differences between traditional Medicare or Medicare Advantage plans, or if MSK and our physicians are in network with your potential new insurance plan, contact the PFS team for resources and information applicable to your care.

At MSK, we are very aware of the growing cost of cancer care and how confusing understanding healthcare insurance can be. Over the years, we have worked to expand our financial assistance and educational programs to meet the needs of patients and their caregivers.

While at MSK, patients are assigned a PFS Patient Access Coordinator, who assists in navigating them through their financial journey, from the start of treatment until their care is complete.

We offer patients financial guidance with medical and nonmedical needs while in treatment, and we have more recently expanded our efforts in assisting patients in applying for programs that help to pay for costly prescription medication.

We have also created our Financial Literacy Program to help educate and address some of the most common questions that patients have – from general insurance terms to Medicare enrollment and prescription co-pay assistance. These programs are now being offered online for all patients who are interested. If you'd like to learn more about these programs, please visit www.mskcc.org/vp and use the keyword “**financial**”.

Surviving Cancer Treatment

By Gretchen Hartman

I was diagnosed with uterine cancer in 2012 and underwent a hysterectomy at MSK. Because of the detection of some cancer cells outside of my uterus, I subsequently participated in a treatment protocol of chemotherapy and radiation, which ended in the fall of 2012. My surgeon very astutely observed at the time: “Now, the real treatment begins.”

Since 2012, I have experienced a variety of post-cancer-treatment symptoms, which I have learned to live with through the help of the dedicated and creative staff of MSK, the support of family and friends, and my own spiritual journey.

The stories of cancer recovery tend to focus on the thankfulness all of us survivors feel — on the beauty of survivorship and participation in life’s continued blessings. However, here, I want to take the time to bear witness as well to what it is like to live with chronic post-treatment symptoms.

Hysterectomy patients can suffer from a myriad of physical and sexual-functioning issues due to vaginal shortening, which is one of multiple bodily changes resulting from the surgery. An MSK support group (Resources for Life After Cancer) I joined became a place where hysterectomy patients were able to share their stories within an empathetic environment. I was referred to the MSK Gynecologic Survivorship Clinic, which continues to provide a variety of helpful symptom treatment options.

In 2014, I began to experience sharp lower back pain, which was ultimately diagnosed as pelvic insufficiency fractures.

This apparently happens to around 7% of patients receiving radiation treatment in the pelvic area. Pelvic bone cells can be damaged permanently, to be replaced by sclerotic tissue, which can — under minimal impact — develop hairline fractures. Consequently, I must use forearm crutches to support my pelvis when I walk outdoors and cannot lift heavy objects, to prevent further pelvic deterioration.

Once again, I turned to MSK, where I was followed by an MSK orthopedist, and continue to be treated by an MSK endocrinologist. My urinary tract was permanently scarred by radiation. To address the resulting condition termed “urinary urgency,” I take medicine under the watchful care of an MSK urologist.

My situation was further complicated last year when, as COVID-19 struck New York,

■ *Continued on page 8*



Gretchen Gretchen is a 79-year-old woman living with her husband in Brooklyn for the past 46 years. She is officially retired from her career as a clinical social worker but still supervises occasionally. She has two adult married children, two grandchildren, and two grand-dogs. She enjoys visiting family, socializing with neighbors and friends, gardening, reading, and traveling to their getaway home in the Catskills. She participates in a book group (a monthly Zoom with Tufts '64 graduates), and connects regularly with a group of women who, in the '80s, reactivated the PTA in their local elementary school. Nine years ago, her husband founded a food co-op, where they are still active members.

■ Continued from page 7

I was diagnosed with squamous cell cancer under my right eyebrow, and again sought the expertise of MSK, this time with their Dermatology Service. Within the first few minutes of my initial visit, my MSK dermatology surgeon discovered another suspicious spot on my face, which turned out to be a very extensive melanoma. Working within COVID regulations, he was able to remove it successfully, and thus (thankfully) prevented its metastasizing. I continue to be followed diligently by a team of MSK dermatologists.

Whether dealing with chronic post-treatment problems or handling the demands of a new cancer diagnosis, I have been treated enthusiastically by MSK physicians, nurse practitioners and nurses, and their highly efficient support staffs. I am forever grateful for their medical intelligence and attentiveness.

No one has ever diminished my requests for help. The message from MSK that they are “with” their patients forever, if needed and wanted, is 100% true.

I am sharing this story to support those survivors like myself, who are grateful every day to be alive and able to put one foot in front of the other ... but who also every day face the challenges of living with the leftovers of cancer treatment, while still aware of the possibility of new cancer growths. We look forward to the time when chemotherapy and radiation are no longer the primary treatment options available. Thanks to the research being conducted at MSK and elsewhere, we are already experiencing alternate and less debilitating treatments for many cancers. Meanwhile, we are continually reassured by the knowledge that we are in the good hands of the caring and skilled healthcare providers at MSK.

Resources for Life After Cancer (RLAC): RLAC welcomes survivors to participate in programs that encourage healing through education and support to live well after cancer. Please see the online calendar at: www.MSKCC.org/SWcalendar

Adult Survivorship Program: The goal of MSK’s Adult Survivorship Program is to help you move forward with your life while carefully monitoring for any signs of disease. The new focus of your care will be your overall health and wellness. We understand that you have been through a lot, and recognize that you may experience new challenges now that your treatment has ended. You can learn more at: www.mskcc.org/experience/living-beyond-cancer

Scan the QR code to be directed to the *Bridges* website and find this issue online.



Patient Editor

Eileen F. Gould

Managing Editor

Alexandria Woodside

Advisory Committee

Wendy Bonilla
Joanne Candela, ANP, MPH
Stacie Corcoran, RN, MS
Zana Correa, NP
Lauren DeMarzo, MSHC
Judith Kelman
Emily McCormack
Nick Medley
Larissa Regala
Clare Thomas

Produced by the Department
of Marketing & Communications

Bridges is a publication of the
Cancer Survivorship Program at MSK.

**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
1250 First Avenue
212-639-7648 or 212-639-8177

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.

**Interested in sharing
your story or receiving
an email copy?**

Please visit
www.mskcc.org/bridges