From the Editor
By Eileen F. Gould

On June 25, MSK held its annual Survivorship Celebration. This year, there were five patient speakers, including a couple who are both cancer survivors. The auditorium was filled with survivors, their friends and families, and doctors, nurses, and MSK staff. It is awe-inspiring to sit in the company of fellow survivors and hear their stories of hope. One of the doctors said to me regarding the celebration, “It is always refreshing and professionally restorative to see so many cancer survivors.” It is also very moving to see so many of the staff who take care of us at the event.

After the speakers, there were information sessions. Among them were a demonstration by Food and Nutrition on healthy summer sides and a presentation by Integrative Medicine on CBD and survivorship, “Truths and Mysteries.” Music and food flowed throughout the evening as people mingled and celebrated.

As I write this, Bridges is celebrating its 11th year of publication. We are excited to have 12 pages in this issue for the first time, rather than the usual eight, and we are proud to have close to 6,000 online subscribers.

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

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Where Are They Now?
By Jearlean Taylor

I am a double ostomate and have been a fashion (editorial and runway) model for 19 years. My picture has been on my city's largest digital billboard. I have been featured in more than 30 published magazines.

I now serve as an active board member of the Baltimore Ostomy Association. My story as an ostomate and a fashion model has gone viral; I’ve been profiled on a number of news channels and media sites. I am so proud to broaden my story through my mini-documentary Pieces of Me. I believe that all things are possible, so look for this project to become a full documentary or film in the future.

I am presently traveling to different cities and sharing my story at conferences, in hospitals, with ostomy groups and youth organizations, and at cancer centers and women’s health groups. I am the CEO and founder of J & Company Modeling, mentoring, teaching, and inspiring fashion models. I am most proud to be mentoring ostomy patients.

In the near future, look for the “Brown Table Talk” (Women Empowering Each Other) event. It started at the taping of my mini-documentary. We happened to be sitting at a brown board table while waiting for the producer to set up the next set. We began to talk about our different struggles and things we have gone through in life. The producer starting filming us in conversation. We are looking to move forward with the talk on a bimonthly basis. It is an outlet to share, to heal, to support, and to help women be free.

We are all different to make a difference!
2018 really threw me a huge bag of “what the heck?” I was supposed to be traveling, running my own business, and drinking Sancerre on rooftops with friends. Spoiler alert: That is not what I am doing at all. Instead, my 2018 was filled with things such as surgery, doctors appointments, and chemotherapy. Most of my summer nights have been spent indoors enjoying a cup of hot water with lemon.

Let’s rewind this tale to the tune of something like Sarah McLachlan. (She really knows how to set a mood.) It was March 2018 and I had just been diagnosed with stage I invasive ductal carcinoma and ductal carcinoma in situ. I had no lymph node involvement and was ER/PR+ & HER2-.. That’s a lot of letters. Essentially, I call it the most basic of breast cancers, as it is the most common. I found my lump in the shower while on a trip with my husband to Iceland. Did I mention I was 35? Turns out, cancer doesn’t always mean death. For me, it means quite the opposite.

Before you start rolling your eyes and telling me I am not normal, I want to throw a disclaimer in here. I do have moments when I get emotional. And sad. And angry. I am not saying those feelings aren’t there. I am saying that I process them in a much more constructive way than I ever thought possible. I continue to amaze myself with how “together” I am. Who is this girl? Certainly not the girl seen popping Xanax before a flight Kristen Wiig–style.

I found my lump in the shower while on a trip with my husband to Iceland. Did I mention I was 35?

So how did I get to this place? I understand that everyone processes unwelcome news differently. I certainly never thought I would be the person to handle breast cancer the way that I am. However, I won’t lie, I get by with a little help from my friends. I attribute a lot of my Zen-like behavior to having a pretty solid support system — one that extends beyond my core group of comrades. Upon being diagnosed, I wanted to know everyone in their 30s who had been diagnosed with cancer. And I started building a network that now I call my “cancer crew.” It is so important to have people to talk to, people who understand your weird chemo side effects and who know what being “too tired to sleep” means. I am also in therapy. I don’t mean just any old therapy. Intense, powerful, good therapy. Ironically, I found my new therapist a week before I was diagnosed. Hands in the air for the universe. I see you. My therapist and I talk about much more than cancer, yet I still attribute so much of my refined coping skills to the work I do on myself. Every single day. If that isn’t a PSA to go out and find yourself a therapist, then I don’t know what is. It has changed my life.

In short, I am a full-on believer in things happening in the way that they need to happen. I don’t condone the universe handing me a cancer diagnosis to teach me these lessons, but if that is what it takes to get my stubborn ass to listen, then so be it. I am a much stronger and balanced human because of my breast cancer.

How’s that for making lemonade out of chemo?
Ask the Survivor:
First Descents

By P. C.

Being a participant was exciting, nerve-racking, thrilling, and heartwarming.

What is First Descents?

First Descents (FD) is a nonprofit organization that gives free outdoor adventure experience trips to young adults ages 18 to 39 who have been impacted by cancer. I went to surf at the beautiful Outer Banks in North Carolina, where we also took time to do yoga in the mornings, go hiking, eat clean and healthy food, hang out at the big beautiful house we stayed at, and explore the small village nearby. There are several other options for adventures, such as kayaking, rock climbing, and more in many different locations.

Why did you decide to participate?

The people were the best part! I met thrivers from all over the country with so many different types of cancers. They all shared the “cancer bond” with me so I could talk to them and even joke about such topics as chemo and radiation. I related to them on a level that I was unable to with my caregivers, friends, and clinicians. The FD faculty members, volunteers, and our own personal chef (who cooked delicious, healthy food for breakfast, lunch, dinner, and snacks) created a welcoming and warm environment. The instructors at the surfing school were very skilled and taught in a safe and encouraging manner.

We still use the same names when introducing ourselves to other FD members around the country and in our local communities. They have so many traditions that I can't tell you about because you have to experience them yourself!

What was your biggest takeaway from the program?

Unfortunate events are going to happen to us no matter what. If, however, we find a way to get out there, try something new, and challenge ourselves, then we empower not only ourselves but our caregivers, families, friends, clinicians, and other survivors, as well. Looking at the other survivors who had gone through worse experiences than me, I was able to realize that it’s not about dying with cancer but living with cancer and being more than it. My biggest takeaway was not even about cancer; I learned that I am capable of being adventurous and should continue being so in my life.

To learn more about First Descents, email programs@firstdescents.org or apply at firstdescents.org/programs/programs-application/.

P. C. was diagnosed with Hodgkin lymphoma while completing her undergraduate studies and is now in graduate school studying healthcare administration. In her free time, she enjoys dancing, reading, and spending time with her family and friends. She hopes to use her experiences to help other cancer survivors.
The Power of Transformation

By Jennifer Penley

Shortly after my 39th birthday, I began experiencing troubling gastrointestinal distress. When the symptoms didn’t resolve on their own, I first went to see my general practitioner and then a gastroenterologist. By the end of September 2011, I had a diagnosis: infiltrating colonic adenocarcinoma. I was stunned, mainly because I didn’t fit the typical profile. I was young (by colon cancer standards), had an active lifestyle with a fairly healthy diet, and lacked a notable family history of the disease.

I had an extremely difficult time coping with the diagnosis; for the first few days, I really lost my mind. My feelings eclipsed my ability to function, and I existed in very extreme mental and emotional states. I had no idea how I was going to survive — if I was going to survive — with my mental health intact.

In addition to the memoir, I regularly work on “active survivorship” as I call it. I stay abreast of new discoveries about my disease and what measures are within my control to mitigate my risk of recurrence. For me, that means eating a mainly plant-based diet, exercising four or five times per week, and regularly following up with my local gastroenterologist for well visits and screening colonoscopies.

I had no idea how I was going to survive — if I was going to survive — with my mental health intact.

In the short period of time between my diagnosis and surgery, I asked my cousin to help me set up a blog. I intended to use the blog as a way to update extended family and friends about my diagnosis and progress, but it quickly evolved into so much more than that. The blog became my therapy. In the safety of my blog, I was able to explore my really heavy feelings and put them out into the world in a thoughtful and articulate way. I dissected my fears, I shared my deliberations over my treatment options, and I invited my readers into my portrayal of the entire experience.

The blog also grounded me. By forcing myself into a highly cognitive space, I was able to temper the tendency of the emotions to commandeer my state of mind. All of that gave me such a sense of empowerment and control, and that was incredibly transformative in terms of my ability to cope and focus on becoming a survivor.

The prep isn’t fun but neither was colon cancer, so it’s all about good perspective. Speaking of which, I’ve also maintained an appreciation for every year that passes and for every day that I am given. When I hit milestones or I watch my sons hit their milestones, I say an extra prayer of thanks for that gift. I encourage my sons to engage in healthy living as well to hopefully minimize their risk of developing the disease, and I openly talk with them about their need to be proactive about this family history when the time comes. And last but not least, I try to be a resource for others who are going through cancer or who are caretakers for someone with cancer, particularly those who are struggling the way I initially struggled. I feel like it’s my duty after having been there myself, and it’s a privilege to help others in that way.

Jennifer Penley is 47 years old and lives in New Jersey with her husband and their two sons. She is a seven-year survivor of colon cancer. Jennifer enjoys reading, writing, photography, and travel, and she has participated in Memorial Sloan Kettering’s Visible Ink program.
What should survivors think about when visiting with their doctors?

At the early visits, especially for teen and young adult survivors, try to gain a clear understanding of your treatment and the potential late effects that are related to your treatment. Always remember that cancer treatment and care are evolving. Some of our recommendations may change as we get new information. We welcome questions about this because we want you to know why we make our choices. And make sure you have a treatment summary or survivorship care plan easily accessible. I always recommend taking a picture of it on your phone.

What are some challenges for teen and young adult survivors?

Young adulthood is already a complicated time of life. People are figuring out so much about themselves and their place in the world then. When you add cancer to that mix, it can lead to some pretty deep thoughts. We also address questions about fertility and having a family later on — something that you might not normally discuss at 21 or 22. There may be some difficulties connecting with peers or feeling like you can’t talk about your cancer diagnosis. We start to address these at the first visit and open the door to resources that may help.

How do you advise your patients to use apps and other technologies in advocating for their care?

Some websites and apps can help you take an active role in your health. I’m very much a fan of food diary apps. They have advanced to include information about popular online recipes and can scan grocery store bar codes to upload information. The food we eat is essential to our health. Having a clear picture of that, even if you don’t plan to change your diet, tells you so much.

Exercise is similar, not so much for tracking but there are plenty of apps and YouTube videos for people to do at home, from stretching to yoga to interval training. The same goes for meditation. There is a lot of interesting research in how meditation can improve mood, symptoms like nausea, even cognitive function. And it’s really terrific that people can access them anywhere in the form of apps and videos.

Symptom diaries are also good. When you meet with your doctor, you can then have a robust conversation about your symptoms and their triggers.

MSK has done a lot to incorporate technology into our care. The Patient Portal is a great way to access lab and testing results. It is a wonderful resource for your survivorship care plan. We have started work on integrating other apps into the MSK platform, as well as working on our own apps.

What should users be aware of with these technologies?

Some smartwatches and other devices collect heart rate, blood pressure, EKG, and other info like that. One concern is that it’s nice to know what your baseline is and when something is not quite the same as usual, but it takes more than a decade of training and education to interpret those changes. The Internet can definitely get it wrong. Think of these technologies as a source of data, not an answer.
My Wellness Journey

By Denise Leprine

“Cancer” is the word we all fear until we are told we have it. Then somehow fear shifts into something different. An opportunity to celebrate each day and the milestones we pass.

Diagnosis and Action

Getting diagnosed with stomach cancer was shocking. I was full of fear, and there was so much unknown. What would this journey be like, would I live or die, would I be a candidate for surgery, would I need chemo, how would I feel, what would I tell my family, friends, and work? Where do I begin? There is no manual on what to do when you are told that you have cancer. So I decided I would treat my cancer similar to a project plan I would develop for work.

Quickly I shifted my shock into reality, did my research, and wanted to know what the best road to well would be. This is how my wellness journey began. I didn’t feel sick, I didn’t look sick, so I was determined not to act sick! I was determined to face my cancer head-on and do my best to live.

Once I met with my surgeon and oncologist, I understood what to expect, which made me feel confident that I could face whatever was ahead. I went through rounds of chemo treatments as well as surgery. I named my last day of treatment “Butterfly Day.” It marked the next chapter of my journey.

Life after Cancer

For months, my life had been turned upside down, consumed with doctors’ visits, tests, treatments, surgery. It became my new normal. Once that part of the journey was complete, it took time to adjust and find a path back to normal life. The first year it was as if I was looking at life with a whole new lens. I needed a lot of adjustments and changes to be sure I felt good physically, mentally, emotionally, and spiritually.

As time continues, I find myself getting back into routines, trying to balance what is most important for my overall well-being. Time helped give me a sense of relief I could put this behind me, however, there is always the fear a recurrence can happen. This seems to empower me more to live in the moment and make the most of each day. Time is funny like that: It flies by, and I know better now that I cannot take a day for granted!

I look at each day as a new gift. It gives me inspiration to share my experience with others and even volunteer my time. I feel this happened to me for a reason, and it’s meant to help others as well.

I remind myself what cancer has taught me and how blessed I am to have a positive attitude, strong faith, and inner strength. This gives me pause to take time to appreciate all the moments. I recognize I do this now with intent and purpose. I look forward to what is ahead on my journey.

Denise Leprine is defined by the passions in her life. She enjoys spending time with her family and special friends as well as focuses on her faith and helping others. Her interests include travel, the beach, cooking or frequenting favorite restaurants, and creative pursuits, including painting and crafts. She is a sports fan and a St. John’s University graduate. She has been an employee at Verizon for more than 30 years.
The cancer experience does not end on the last day of treatment. Many people face physical, practical, and emotional adjustments as they finish treatment and try to resume a sense of normalcy. Dating after cancer can be overwhelming. Concerns about when and how to disclose a cancer history are common among survivors.

First, there is no right time to tell someone you are dating that you had cancer. Cancer is not a shameful secret or a crime to be confessed. You do not owe this disclosure to anyone. Medical information is personal and private. You get to decide if, when, and how much to share.

Some survivors want to share their cancer experience and the profound effect it may have had on them. They may worry, however, about their prospective partner’s response.

Remember: Rejection because of your cancer history is about the other person’s limitations, not yours.

Dating can be difficult for everyone. Cancer survivors can feel vulnerable in the dating world. Physical changes related to treatment — fatigue, scarring, loss of a body part, cognitive changes, infertility, pain, and changes in sexual function, digestive function, and mobility, to name a few — can have a profound impact on body image, sexuality, and self-esteem. It can be helpful to practice recognizing negative self-talk if it occurs. Cancer does not leave you damaged goods.

An empowering question to ask yourself is: How has the cancer experience changed my criteria for a partner?

Consider focusing on your own comfort when on a date. An empowering question to ask yourself is: How has the cancer experience changed my criteria for a partner? You do not need to stay in an unhappy relationship or date someone based solely on an expression of interest.

Because dating after cancer can present unique challenges, MSK’s Resources for Life After Cancer (RLAC) offers the program Dating and Disclosure multiple times a year in virtual and in-person formats. It is set up as a discussion group led by a clinical social worker. It focuses on the complexities of dating after cancer treatment. Young adult survivors may have distinct concerns relative to their developmental needs and life stages, and so Dating and Disclosure for the Young Adult is also offered.

RLAC extends MSK’s mission to provide the best cancer care anywhere and creates a community of support, education, and hope. Other services include educational lectures, support groups, counseling services, advocacy, and community referrals. Survivors who have finished active treatment are welcome to participate.

For more information, email RLAC@mskcc.org or call 646-888-8106. All programs are free of charge, but registration is necessary.
Three years ago, I received a phone call from my cardiologist. He stated that I needed to stop what I was doing and rush to an emergency room. I told the doctor that I felt fine and that I was at work. He said, “You don’t understand the urgency of what I’m talking about. Please call your family and meet me in the ER.” I packed up my things, called my wife (a very tough phone call), and drove to my local emergency room. At that point I found out that my body was depleted of blood, and I had a very good chance of my organs shutting down. I knew I had been bleeding for a while, but a lack of education in the matter and simply not wanting to go to the doctor set off a sea of emotions. There were highs and lows as I performed all of the tests they asked and shortly thereafter was diagnosed with bleeding from the colon and, ultimately, colon cancer.

Within two weeks my story went from “We got the cancer” to “It’s stage IV with metastasis to the liver, and it’s inoperable.” I sought out liver surgeons at recommended hospitals, and the outcome of the visits was grim at best. I knew in my soul that there was another plan for me, and if cancer wanted a fight, it just found one! My family insisted on Memorial Sloan Kettering. Being as stubborn as I am, I kicked and moaned the entire way. I was overwhelmed to say the least, but after sitting with my doctor at Memorial Sloan Kettering, I knew I had no choice. While doctors at other hospitals were giving me three to five years to live, my doctor at MSK looked me in the face and said, “I’m going to save your life.” My wife began to cry, and so my journey with Sloan Kettering was underway.

Three years later, my liver is free and clear of cancer, thanks to a liver pump and a brilliant surgeon. I developed some nodules on my lungs, but in true Sloan Kettering fashion, my oncologist is helping me fight that battle with great success.

Through my battle I have continued to work 60-plus hours per week running an automobile dealership. I have become a minister of the Christian faith, and maybe the greatest thing I have done is refocus my priorities. I let cancer teach me that I am here to help others in their journey. I focus on teaching at work and loving at home. Every morning I can go to work and every day I can love my family and let them love me back is a day that I have beaten this disease. I continue to ride my motorcycle and walk on the beach with my wife.

I have hope of tomorrows but learned to live for today.

As far as I am concerned and all those who I love, Sloan Kettering has come through with more than I could’ve ever hoped for. Cancer is not a joke. Yes, cancer destroys and ends lives, but the professionals at Sloan make it manageable and provide hope on every floor! My friends (receptionists, nurses, doctors, and CMAs) at MSK Basking Ridge make it a livable, winnable lifestyle.

Thank you, and God bless all those at Sloan Kettering!
Cancer-related fatigue (CRF) is one of the most common and distressing side effects of cancer and its treatment. It is different from regular fatigue. CRF does not go away with rest, and even the smallest amount of activity can be exhausting.

While CRF is common, it can affect people differently. Some describe it as feeling weary, worn out, or slow, or as having difficulty focusing and concentrating. Others may feel moody, irritable, sad, or frustrated. One person may be too tired to get out of bed. Yet another person may be able to continue working and do most of their daily activities. Fatigue can improve after treatment. However, cancer survivors often have fatigue months after treatment ends. The following strategies may help manage the symptoms of CRF.

### Save Your Energy

Prioritize the tasks that are most important and do those first. Plan ahead and spread those activities throughout the day, making sure to build in breaks to rest. It may be difficult to accept that you cannot do everything you want or used to do.

Work slowly to conserve the energy you do have. Keep a chair nearby and sit whenever you don’t need to be standing. Sitting while getting dressed or preparing food for meals helps you save energy for later. A shower chair may also be useful as even standing while bathing can be exhausting. Ask for help from friends and family, especially with jobs that require more energy, such as cleaning your home, preparing meals, or doing laundry. People are often happy to help and appreciate being assigned a specific task. Keep frequently used items easily accessible and within reach. For example, store daily dishes, pots, and pans on the countertop to avoid having to reach for them. Place refrigerated food on the top or middle shelves so you don’t need to bend and further exert yourself.

### Get a Good Night’s Rest

Avoid caffeine, especially later in the day. If you take a nap, do it earlier in the day, and keep it less than 30 minutes. Set an alarm to wake you.

### Stay Active

Participate in regular moderate exercise but not too close to bedtime — it can prevent you from falling asleep. Walking is a great way to stay fit and minimize fatigue. If you are concerned about physical activity, your doctor can refer you to an MSK occupational or physical therapist. We can help set up the right exercise routine for you.

“Let’s just say we will be seeing a lot of each other for the next six months.” This was the answer from our MSK oncologist when, gripped with terror, I asked her how long our 8-year-old daughter might live.

That was in March 1984, just a couple of weeks after her diagnosis of a tumor in the pituitary region and surgery at New York Hospital. A more specific diagnosis was not available based on the tissue from surgery, so radiation was the first course of treatment: six weeks of daily trips to Yale New Haven Hospital, nearer to our home.

When Lizzie relapsed shortly after that treatment ended, there was a blood marker enabling a more specific diagnosis: an endodermal sinus tumor. It was “the rarest of the rare,” we were told, and doctors suggested chemo. There were two more remissions and heartbreaking relapses over the next year and a half, followed by treatment with a new regimen devised by another MSK pediatric oncologist for a different deadly cancer.

This turned out to be a miracle for us, and today, Lizzie is a wonderful 43-year-old enjoying an independent life and good health, with a special quality to her grit and optimism that stems from her years of being different from other kids and dealing with difficult treatments and side effects.

The long-term side effects of aggressive treatment for this cancer have been many. Minor problems include replacement hormones for those Liz no longer produces on her own, a result of the loss of pituitary function from both the tumor itself and radiation. The tumor also grew into one of the cranial nerves, leaving her right pupil always dilated. Radiation led to two skin cancers on her scalp, found early and easily treated.

Chemotherapy led to other, more threatening complications. The most difficult for Liz is the hearing loss, which became more severe over the years; fortunately, a cochlear implant three years ago, and diligent retraining, has greatly improved Liz’s hearing.

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Sara Olson, her husband, and their two children were living in Connecticut when their daughter, Liz, was diagnosed with cancer at age 8. Now a long-term survivor, Liz works in Boston as a geriatric social worker. She is active in the cancer survivor community and the hearing loss community. Sara recently retired from her work as a cancer epidemiologist and now enjoys volunteering, traveling, and visiting grandchildren in Colorado.

From left: Liz Olson, who was diagnosed at 8 years old, with Sara Olson, her mother and a retired MSK epidemiologist.
Continued from page 11, Many Miracles

A kidney tumor was found incidentally on a CT scan for appendicitis, allowing for surgery saving half the kidney. Again, medical miracles were ours. Not relying altogether on miracles, Liz has screenings every year for colon, esophageal, skin, and breast cancers — a lot of tests for a young person. And her life is saddened by the loss of friends who have not survived their cancer or its long-term effects.

During Liz’s treatment, we joined local support groups for children’s cancer and tapped into personal strengths we didn’t know we had. My mantra was “Once, there was the first child cured of leukemia, and there is no reason why Liz can’t be the first person cured of this.” After the initial diagnosis, I rarely cried, telling myself that there would be a lifetime for crying if she died.

Our daughter’s experience with childhood cancer changed my life professionally as well as personally. I was working as an analyst in market research when she became ill, but I could not envision returning to promoting consumer products. Building on my research background, I enrolled at Columbia to study epidemiology, investigating the lifestyle and genetic factors that influence people’s risk of disease. I eventually joined the Epidemiology Service at MSK, retiring earlier this year after 24 years. The progress against cancer over this time period has been remarkable: Greater understanding of risk factors has led to lower incidence rates, and new treatments improve survival. Childhood cancer survivors like Liz face better futures because of research on side effects. We are indeed grateful for our miracles and optimistic for the future of people with cancer.

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From left: Survivorship Celebration speakers Josh Gelman, Selma Sulejman, Samantha Hacker, Alex Marcus, and Marla Edlin with Adult Survivorship Program Director Stacie Corcoran.

Survivorship event

From Left: Bridges Managing Editor Alexandria Woodside, Patient Editor Eileen Gould, and Designer Larissa Regala.

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