Spring 2014

Bridges

Connecting Cancer Survivors

Erica (left) is a retired schoolteacher. She lives in Riverdale, New York, with her husband, Rabbi Joseph A. Brodie. Her short story "Owing a Debt of Gratitude" was published in the Holocaust section of Chicken Soup for the Jewish Soul.

Claire-ing

By Erica S. Goldman-Brodie

Claire-ing? It's a word I coined in honor of Claire Tunick. I was diagnosed with stage IV clear cell endometrial carcinoma in September 2004. Claire had been diagnosed more than a year before with stage IV diffuse large B cell lymphoma with mediastinal lymph node involvement and was in remission at the time of my diagnosis.

Claire and I had taught in the same school for just a few years. When I was diagnosed, Claire was one of many who offered to help — anything I felt like talking about, she would make herself available.

How do you reach out for help? As Claire and I both like to read and write, I found e-mail worked the best. It's a way to release tension and express thoughts that is comforting and comfortable. We can read and reread parts of letters that have special resonance. It seemed only logical then that I approach her in an e-mail. I don't remember the first question. I can look it up. I have saved all the e-mails — more than a hundred of them! We're thinking of turning them into a book.

Why was Claire's help so special? Claire was open, non-judgmental, and very approachable. There wasn't any topic that was off-limits. We discussed everything — from the nausea that would come with a particularly strong and repellent odor in the bathroom and what to do about it (spray before you go) to how to handle inertia

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If you are interested in submitting your story, please visit **www.mskcc.org/bridges**

In This Issue

Memorial Sloan Kettering Cancer Center™

Editorial

by Eileen F. Gould

Cancer treatment is continually evolving and improving. Aggressive state-of-the-art treatment in the 1970s and 1980s saved lives, but the long-term effects were unknown. As cancer patients live longer than ever before, some face secondary cancers, premature heart disease, pulmonary insufficiency, muscle fibrosis, and psychosocial distress. As cancer treatments have become more effective, there is an increased focus on understanding and addressing the late effects of cancer treatment to improve our quality of life. For example, clinicians are developing screening guidelines and risk-reduction strategies for post-treatment patients. We are fortunate that Memorial Sloan Kettering is at the forefront of this kind of comprehensive cancer survivorship research.

A Special Survivorship

By Brenda McDonnell

Brenda is a special educator who provides developmental intervention for children from birth to three years old. She lives in northern New Jersey with her husband, Jim, and son, Brian. Brenda enjoys hiking, traveling, reading, and writing.

Recently, our extended family celebrated my son's tenth birthday, a momentous occasion filled with lots of laughter, love, and food! There was a time not so long ago that such a party would not have been possible due to Brian's special needs. Loud noises, unfamiliar routines, and too many people at one time would have caused a major meltdown. Many times in the past my husband, Jim, and I would have to leave events because Brian could not handle them. But with time, practice, and opportunity, Brian has learned to cope much better in social situations, and his most recent party, with 42 people in attendance, was a testimony to how far he has come over the past decade. What a priceless gift!

I am also the very fortunate recipient of a present on Brian's birthday for the past four years. The gift that I receive is cancer survivorship. I was diagnosed with colon cancer on Brian's sixth birthday and remember initially feeling so shocked and afraid. How could this be happening? How will Jim cope alone with our special son if I don't make it? It was very overwhelming at the time, but by the grace of God and the tremendous support of family, friends, and a stellar medical team at Memorial Sloan Kettering, I was able to move forward. Our family was already familiar with MSK, as my brother had been treated there for prostate cancer nine years before my diagnosis. We were impressed with the collective medical experience and quality of care that my brother had received. I knew that MSK was the right choice for my situation.

I had a wonderful colorectal surgeon at the helm of my surgical care, which resulted in a successful left hemicolectomy. My pathology results indicated a stage III colon cancer, due to one pesky lymph node, so I began chemotherapy one month after surgery every two weeks over a six-month period. My oncologist was very helpful and knowledgeable during this journey, along with the outstanding nurses assigned to my care. There was always a plan in place to manage any challenge or side effect, which was especially important during the postsurgical recovery and after chemo sessions.

During chemo, I would write about my experience through a blog, to inform family and friends of my progress when direct communication was not always possible. It was a very cathartic

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Ask the Professional:

Guidance on Filling Prescriptions

By Kathryn Ciccolini, RN, BSN, OCN

Kathryn is dedicated to constant excellence, application of the nursing process in patient care, and healthcare process improvement. As a clinical nurse working on the Dermatology Service, she has considerable experience with insurance coverage of prescriptions. Prior to coming to Memorial Sloan Kettering, she worked at a pharmacy.

Common scenario: A patient who received a stem cell transplant suffers from chronic graft-versus-host disease. His dermatologist recommends that he use a prescription-strength moisturizer. He takes the written prescription to his pharmacy and intends to pick it up the next day. When he comes back, he discovers that the cream has been denied by his insurance and will cost him $600. The patient purchases the moisturizer at full cost, unaware of his other options regarding coverage.

What questions should I ask the pharmacist when dropping off a prescription?

Before you leave the pharmacy, always ask if the prescription is in stock and if it is covered by your insurance. If it is not in stock, ask if it can be ordered and how long the delivery will take. If the prescribed drug is denied insurance coverage, ask the pharmacist the reason and what the next steps are.

What are my options if the prescribed drug is denied by the insurance company?

Insurance companies may require a prior authorization (PA) before agreeing to pay for the prescribed drug. Prior authorization is a process by which your insurance company requests more clinical information regarding why you need the drug. The pharmacist should contact your clinician's office directly. The clinician's office should then initiate contact with your insurance company and send the information directly to the insurance company.

Urgent requests are usually processed within 24 hours and other requests take between 24 and 72 hours. Generally, the healthcare practitioner's office must respond within ten days or the PA may be automatically denied.

What can I do while my medication is in the process of an approval that may take several days?

You may ask a pharmacist for a generic product that is similar to what your clinician prescribed, and that is covered by insurance. The same medication may also be available in a different vehicle (for example, a lotion instead of a cream) that would be covered by your insurance. In some cases, an over-the-counter option may also be available at your pharmacist's recommendation.

What happens if the prior authorization is approved?

You can fill the prescription. Typically, refills are covered for a year. After a year, the insurance company may require another PA approval.

What happens if the prior authorization is denied?

If the insurance company denies the PA, they should inform your clinician. At that point, you may appeal the insurance company's decision. This requires your clinician to provide supplemental information including a letter of medical necessity. Urgent requests are processed in one to two days

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A Journey of Transformation

By Scott Baker
Co-author Ellen J. Greenfield

Scott is a husband and father of two sons. He has worked as a bridge engineer for the New York State Department of Transportation for 20 years. He is a four-time cancer survivor.

I know it sounds counterintuitive when I say this, but I have actually found the greatest happiness over the past two years, despite two of my most difficult battles with cancer. I know that I have been a better husband, father and friend than at any other time in my life. And while I don't recommend it, this experience has taught me the importance of finding inner peace and commitment to change where it is needed.

The journey began in 1999, when I was 29, working as a bridge engineer for the New York State Department of Transportation and dating the woman who is now my wife and mother of my two sons, seven and eight years old. I was diagnosed with systemic non-Hodgkin lymphoma, underwent surgery, chemotherapy, and radiation, and was out of work for five weeks. Then, in 2006, I suffered a recurrence, which required a stem cell transplant, and I was out of the game entirely from about April to July.

The one thing that kept occurring to me during my second illness was that there was a lesson there. I was being told, in no uncertain terms, that I needed to change and be the best person I could possibly be. But despite that knowledge, I kept going back to my old self. So maybe it shouldn't have come as a complete surprise when in 2012 I was once more diagnosed with cancer — this time in my central nervous system, my brain. This recurrence brought me to MSK for treatment and a second stem cell transplant.

Treatment was aggressive and rigorous and by now my sons — who had already lived through three of my cancers — were old enough to know just how sick their dad was. I was in the hospital for more than 100 days in one calendar year. My wife was by my side for most of this time. How that looked from my boys' perspective, I can't imagine. When we spoke to their teachers, they said they didn't even know anything was going on in the family. Was this denial or faith? I may never fully know.

For my part, I never believed that my life was over, only that I needed to change it, and for good. It took hard work and a complete reprogramming of the way I think and respond to the world. I became painfully aware of how much pressure and stress people put on themselves and I knew I had to remove that factor. I used to try impose my views on others. I used to be quick to anger. My life depended on learning to change these things.

One moment that I recall vividly: I was sitting in a chemo treatment room with other patients. We began to talk and then to laugh. Not one of them was bemoaning their fate. In fact, they were some of the happiest people I'd ever met. Why? I asked them. And the answer was a single word: gratitude. We were all grateful to be alive. I carry that memory with me daily.

Since treatment, I've been a stay-at-home dad, which has allowed me to build a strong relationship with my boys. We talk. They tell me how they feel. We discuss mistakes we've all made. We grow together. With the help of my family, I have steadily improved, physically and cognitively, to the point where I've been coaching my sons' baseball teams and have now been cleared to return to work. I can once again play golf, a game I love.

I also maintain a solid connection to the community of cancer survivors. I have been fortunate to work with a number of support groups, including the LIVESTRONG program at the Saratoga YMCA, where I am a mentor to other survivors. That work has really brought me back to life.

The Dialogue of Cancer

By Kris Costa

Kris was born in Staten Island, New York, and currently lives in Scottsdale, Arizona, with her husband, three children, two dogs, and two horses. Kris participates in Arizona's chapter of Light the Night walk as a survivor volunteer. She has spoken on Capitol Hill as a patient advocate and recently passed her therapy dog handler's test.

Every survivor has a story.

Mine started out on my way home from work one sunny June afternoon in 1983. My mom came to pick me up and we were riding in the car. I still remember the feeling of freedom as the wind blew through my long brown hair. Spring was always a season of rebirth to me after the long New York winters. I closed my eyes and smiled, completely unprepared to hear the next words spoken to me.

"What's that on your neck, honey?"

Those words came from my mother as she noticed the lump embedded in my collarbone. I was an only child of young parents, 18 years old, a college freshman, coming home from my first summer job, where I had worked for only four weeks. At that moment, everything changed.

I would never experience a sunny day in the same way, and I would never forget the shift in reality as her words penetrated my soul. My beautiful mother, concerned yet fearlessly collected, drove me immediately to the doctor.

There are so many words cancer patients hear. They are foreign, confusing, and terrifying. Words for the diagnosis of what is going on uncontrollably in your body; words for tests, drugs, machines you will be hauled in and out of, surgeries in hospitals you cannot fathom membership in. The words of your future become lost in a void of transition as you move from the precancer world to the post-diagnosis world. Mine was Hodgkin's disease, IIA. Even now, the words I spoke that beautiful June evening echo: "Daddy, I don't want to die." I sobbed in my father's arms as he courageously held me.

And so it began.

Our journey included surgery, chemotherapy, radiation, side effects, anxiety, and a sense of heightened awareness that is hard to explain. However, it also included unexpected gifts beyond imagination. I clearly remember my hospital buddies whom I saw on a regular basis, and the life lessons they taught me. They unknowingly carried me on their air. They were not going to let this disease take their spirit. These people taught me how to live, even as some of them died.

I lived, graduated college, married, opened businesses, and birthed three children. In an emotional switch, I lived to see my dear oncologist die. He gave our family the subtle gift of hope through his unusually casual demeanor. I will forever honor our memories of him and live fully, as he always wanted me to.

I am here today because others have sacrificed in so many ways, and I will not waste precious time. Now, my world centers on words like serve, empathy, persevere, integrity, boundaries, purity, action, passion, and hope.

I have always believed that one person can make a difference. Save just one life and you save worlds. I've always hoped to tell my children that cancer was a disease mommy had a long time ago, but that people don't get it anymore. I believe one day that will be true. I believe in hope; it is real, it is strong, and it is bigger than fear.

I am a cancer survivor.

Resource Review

Survival Lessons

Reviewed by Ellen J. Greenfield

In her lifetime, novelist Alice Hoffman has given her readers the pleasure of thousands of pages, but with her recent book, *Survival Lessons*, she lets a mere 83 (tiny) pages speak volumes about the value of loving and living wisely and with self-compassion. She speaks not only to cancer survivors like herself, but to all of us when she advises, "There is always a before and an after. My advice, travel light. Choose only what you need most to see you through."

Each chapter in this little gem of a book is a stirring meditation on how to make good choices — in heroes, friends, acceptance, sharing, future plans, and past memories. This book is small enough to fit in a pocket and large enough in scope to fill you with hope.

In the end, she advises: Choose love. Who could argue with such good sense?

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and other requests may take up to a week. If approved, then you can get your prescription. If denied, then you and your clinician can discuss if the medication is affordable for you to purchase or if there is an alternate therapy that could be effective and affordable.

How can I determine what medications are accepted by my insurance company?

Insurance companies may publish a formulary (a list of drugs covered by your insurance) or a preferred drug list, which provides alternative options for medications that are not covered and PA/coverage parameters. You can ask that these lists be mailed to you or you can find this information on the insurance company's website. Some insurance companies also have a tool for estimating the cost of prescriptions. If you need help understanding this information, you can ask your pharmacist or clinician.

Additional Helpful Tips

- **At the pharmacy**
  - Provide your insurance information upon dropping off the prescription.
  - Always ask if the medication is covered and if it is in stock.
  - Keep your personal information (address, phone number, etc.) updated.
  - If a medication is rejected by your insurance, be proactive and speak to your pharmacist so he or she can contact your clinician to determine alternative options.
- **With your clinician**
  - Be sure your prescription is complete and contains the following: patient's name, patient's date of birth, medication, dosage, quantity, refills, and instructions.
  - Ask your clinician to provide a letter of medical necessity up front for drugs that have required PA in the past.
  - Ask what the clinical indication (reason) is for you taking the drug.
  - Ask if generic brands are available and acceptable.
  - Ask if your medication needs to be sent to a specialty pharmacy for special mixing.
- **With your insurance company**
  - Review what medications are on your formulary.
  - Review the website and seek out estimating medication cost tools and formulary lists.
- **General**
  - Do not pay the full price for a medication until exhausting all other possibilities.
  - Track the effectiveness of all treatments: what worked, what did not work, what made the condition worse (prescription medication, over-the-counter medication, and home remedies). This information helps with the PA process.
  - Bring a list of drug allergies and medications to your appointments and the pharmacy.
  - Keep the labels with the instructions on how often to take or where to apply medications.
  - Make use of payment assistance programs:
- **NeedyMeds** (www.needymeds.org/indices/pap.htm)
- **Medicare's Help Paying Costs** (www.medicare.gov/your-medicare-costs/help-paying-costs/get-help-paying-costs.html)
- **Prescription Assistance Program** (www.pparx.org)
- **American Cancer Society Prescription Drug Assistance Program** (www.cancer.org/treatment/findingandpayingfortreatment/managinginsuranceissues/prescriptiondrugassistanceprograms/prescription-drug-assistance-programs-toc)
- **CancerCare Co-Pay** (www.cancercarecopay.org/)

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experience and enabled me to do something constructive. I tried to find humor during this time in any shape or form for the sake of my sanity and well-being. I also prayed a lot and knew that many people were praying for me as well. All of the above resulted in the nurturing of my body, mind, and soul. I was ultimately able to cope better through treatment because I used my "tools of survivorship," one day at a time. I still struggle with anxiety right before an oncology follow-up appointment or a CT scan, but time being the great healer has quieted those fears so that they are not quite as loud as they were four years ago.

I know that I am blessed and fortunate to be here today. I am so grateful for Jim, my rock through all seasons of life, and our beloved Brian, a courageous little boy who shows me daily how to live life with grace. Celebrating survivorship on my son's birthday each year is truly is the best gift that a mom could ever receive.

Resources for Life After Cancer (RLAC)

RLAC welcomes survivors to participate in programs that encourage healing through education and support.

Please see the online calendar at:
www.mskcc.org/livingbeyondcancer

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.

A Guide to
Understanding Study Results

By Emily Craig Zabor, MS

Cancer patients and survivors are confronted by many different numbers throughout the course of their disease. Whether hearing them from a doctor or reading them in a journal or news article, without some knowledge of statistics these numbers can be difficult to understand and interpret. This is a guide to understanding some of the numbers most commonly cited in cancer research studies.

Statistical significance is the probability that an effect is not likely due to just chance alone. A **p-value** is a measure of how sure we are that a result has not occurred by chance. A 95 percent certainty that a result did not occur by chance corresponds to a p-value of less than 0.05, or <0.05. For example, the statement "treatment A was associated with better overall survival as compared to treatment B (p=0.035)" indicates that the p-value was 0.035, which is statistically significant at the p<0.05 level, corresponding to 95 percent certainty in the result.

A **hazard ratio** represents the chance of an event, such as recurrence, occurring in one group divided by the chance of that event occurring in the other group. A hazard ratio of 1 indicates that the risk is the same for the two groups. For example, 2 divided by 2 is 1. A hazard ratio <1 indicates reduced risk, and a hazard ratio of greater than 1, or >1, indicates increased risk. For example, in a study comparing recurrence rates between treatment A and treatment B, a hazard ratio of 1.5 means that the patients who received treatment A had 1.5 times increased risk of recurrence as compared to patients who received treatment B.

Confidence intervals are a range of values. The 95 percent confidence interval is the most common, and it represents the range of values that are plausible for an effect with 95 percent certainty. A study that says "treatment A was associated with increased risk of recurrence as compared to treatment B (HR: 1.5, 95 percent CI: 1.2 – 2.6)" is reporting a hazard ratio (HR) of 1.5 with a 95 percent confidence interval (CI) of 1.2 – 2.6, which means that we are 95 percent certain that the true association falls somewhere between 1.2 and 2.6.

There are many factors to consider when reading and interpreting the results of research studies, and it can be difficult, even for experts, to determine what results to believe. While factors such as study design, sample size, and patient characteristics are important to consider, a loose grasp on what the numbers mean is a good place to start.

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and listlessness. Claire's help was great because she kept her advice short. She answered the issue at hand. She didn't scare me with what might happen, what could happen, or what had happened to her. She sent me hats with instructions on how to wear them: with a wig, without a wig, to the side, pulled back, pulled down. But most important, Claire could read between the lines and determine even better than I what was really causing discomfort. I could show her e-mails to my husband, and coming from her it was easier for both my husband and me to take the advice she gave and to discuss the matter calmly.

Thanks to the amazing staff of caring, capable doctors, fellows, nurses, aides, and greeters (whose smiles brightened every day of treatment) at MSK, both Claire and I are in remission. Claire is my Elijah, the prophet who surprisingly shows up and does exactly what is needed to remedy a situation. During those nine months of treatment, we did not speak once. But we did e-mail, often several times a week! Nowadays, we get together every few months just to shoot the breeze. Our health hardly ever comes up, but we each heave a huge sigh of relief for ourselves and each other when the CT scans and our blood work come back with good results. We've each had a few glitches, but we are healthy, happy, and living life to the fullest — enjoying and savoring every minute.

Claire is a beautiful, articulate, caring, fun, and most vivacious person. Just ask any of her students and colleagues who know, admire, and love her. Claire modeled "Claire-ing" so well — I only hope I'm doing it justice as I pay it forward by Claire-ing for others.

Reflections on
Relationships

Below are thoughts from participants who answered writing prompts at the Fall 2013 Visible Ink Writing Festival. Established in 2008, Visible Ink offers patients at Memorial Sloan Kettering the opportunity to work one-on-one with an experienced mentor on a writing project of their choice. The program is free of charge and open to all interested patients, regardless of their writing level or experience.

Is it possible to repair relationships that were strained during your cancer diagnosis?

Yes, but only if the relationship was originally built on real friendship and trust. Patience is crucial. It takes some friends longer to absorb the shock of your diagnosis, and then start to act like friends again. However, some relationships cannot be mended and you just have to let them go.

How do you forgive and let go of relationships that suffered after your cancer diagnosis?

Forgiveness is a bitter pill, but a great cure.

Forgiving and letting go of relationships is a mental, emotional, and spiritual process. Sometimes I miss someone so much that I'm willing to forgive and forget the pain involved, but then I remember how I need to care for myself and try as hard as possible not to call or see the person who is toxic for me. It is a long, arduous process.

You take it one day at a time. At first you feel hurt and disappointed but gradually you let go and move on, realizing that nothing remains the same in life. You become enlightened as to who are your real friends and who are fair-weather friends. You pray a lot; you put on a happy face and smile. Life will become less stressful, and your load will become lighter.

How do you sustain relationships that blossomed during your cancer journey?

Stay in contact with your friends via e-mail and phone. Check up on each other. Let your friends know you truly care about them. Stay positive and encourage hope. Meet up when you can. Let them vent when they feel the need. Reach across time and space to share in the blessing of life. Be a support system for each other.

There is a bond that never goes away, though you may not be with them every day. It is like an ongoing conversation.

Memorial Sloan Kettering
Cancer Center™

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Connections
is an online community for patients and caregivers. It provides a venue for conversations, support, questions, and companionship.

To register, visit:
www.mskcc.org/connections

Rising Voices
is a chorus for patients and survivors sponsored by the Integrative Medicine Service. The chorus is open to all MSK patients and is free of cost.

To join, contact Kelly Williams at
williak9@mskcc.org.

Patient – to – Patient
We are grateful for the support of our patients and family members. If you are a former patient or family member who has completed treatment please consider becoming a Patient-to-Patient Volunteer.

For more information, contact the Department of Volunteer Resources at 212-639-5980.

If you would like an e-mail copy of *Bridges*, please sign up at www.mskcc.org/bridges to join the mailing list.