

Stage IV Breast Cancer: *It's About Time*

Malaya Southern sits at her “station” at Rutgers Cancer Institute of New Jersey. Most of her Mondays are now dedicated to the steady drip of chemotherapy drugs that she hopes will buy her valuable time, maybe enough time to stave off the Stage IV breast cancer that threatens her life, maybe enough for a new and better drug or combination of drugs to be identified to beat back her disease. She is 33 and brimming with plans for the future. Like most newlyweds, she hopes her marriage will endure the tests of time, but in her case, those tests are here now and they are tough.

Is this young woman knowledgeable about her disease and its treatment? Oh yes, she knows her blood count, understands when it is too low to allow for an infusion of the drugs that course through her system to attack the cancers that have set up a home there. She rattles off the long, unpronounceable names of the therapies that have already failed her, and those that may yet prove to be powerful cancer-combatants. She asks pointed questions of the nurses who stop by, and they respond as if she were a fellow health professional. They like this young woman a lot; you can tell. Southern is afraid that if her blood counts are low, she will not be able to get her weekly dose of “lifesavers.” But on August 26, the day of our meeting, the nurse stops by to tell her the results of this morning's round of blood tests, giving her the green light for today's regimen.

Her spirits soar; at least for today those drugs will have the chance to slow-down the advance of her potential killer.

It may be hard to see someone in the throes of heavy-duty cancer treatment as anything but a sick patient. But in the case of Southern, it is actually hard to see her as a patient at all. Despite losing all the hair from her head in June (It's growing back a little, she says.), she jauntily sports a print bandana that looks downright attractive on her. The beautiful smile she offers on a frequent basis has not dimmed; her vivacious spirit does not seem to be drooping; she goes to her job as a financial assistant four days a week; and although contact sports are dangerous for her right now, she serves as manager of the roller derby team in Red Bank that has rallied so passionately to support her. Add to that her obvious intelli-

BY EVE JACOBS ■ PORTRAIT BY JODY SOMERS



Malaya Southern is running "the marathon of Stage IV cancer" as she calls it, but everyone in her life is running closely by her side. Keeping a positive attitude, she continues to connect with those whom she loves, and takes every day as it comes, appreciating each one for what it is.



Malaya Southern with husband Sean Kelly and trusty companion Bentley. • Below: Southern earlier this summer in a photo shoot to promote a breast cancer fundraiser with her roller derby team Red Bank Roller Vixens.

gence and her ability to express her innermost thoughts and emotions, and what you have is a young woman overflowing with life.

Why did this awful thing happen to her? Why now? Why was her disease already so advanced at diagnosis? "I just don't know," she says, but she doesn't waste much time on those unanswerable queries. Her mother, who often keeps her company at the Cancer Institute of New Jersey during those long chemo-Mondays, appears to be healthy; no one in her family (that she knows of) has ever had this disease; and she's been tested, and found negative, for the BRCA1 and 2 genes, frequently implicated in genetically-based breast cancer. "I've always eaten healthy foods; I live a healthy life—take spin classes, do yoga," she says. On top of that, she's an athlete and has been in top physical shape her entire life. She has no known risk factors for this cancer or any other, according to Deborah L. Toppmeyer, MD, an oncologist specializing in breast cancer and director of both the Stacy Goldstein Breast Cancer Center and the LIFE Center at the Cancer Institute.

"Malaya has triple negative disease," explains the physician, who is also the Institute's chief medical officer. "This means her cancer is not estrogen dependent, not progesterone dependent, and does



not express HER2 protein. That also means there's no great target for a drug to stop the cancer's spread." This type of breast cancer tends to hit younger women, more often African Americans, accounts for about 15 percent of all breast cancers, and is more of a challenge to treat because there is no clear-cut therapeutic target, she states.

Seeking Answers

The story of this young woman's diagnosis might shock even those familiar with cancer's many guises. Most of us associate acute chest pain with heart attack, not breast cancer. What brought Southern to her local doctor several times over a three-month period beginning in August 2012 was a sharp, persistent pain in her sternum, an indication, she thought, of a fracture from a roller derby skir-

malady she did not remember. She's a member of the Red Bank Roller Vixens, and broken bones are not infrequent in that fast-moving world. In fact, she had an ankle fracture just a couple years ago. Although the pain in her chest was often pretty bad, she had been assured on her first two doctor visits that the X-rays showed nothing out of the ordinary. A pulled muscle was likely the culprit.

But in October 2012, she was determined to get an answer. The pain appeared to be getting worse, requiring frequent doses of ibuprofen to keep it in check. Southern's level of concern shot up. So, when the roller derby season ended, she made a trip to the ER, determined to get answers. On this go-round, the diagnosis was definitive and depressing: strangely, the first X-ray still showed nothing, but the blood work signaled an alarm. "The nurse said, 'We need another vial of blood and a CAT scan,'" she recalls. "The ER doc came in a little later and sat down. I remember her words: 'I'm afraid it's bad. It's really, really bad. There's a tumor on your sternum that's causing the pain, and another on your breast. We're 95 percent certain it's breast cancer.' And I remember thinking: 'I don't want to die.'"

"The tumor on the sternum was large," Southern says, tapping her chest wall dead center. "It was right here." What followed her diagnosis was a dizzying round of testing and doctor-consults that left her feeling confused and unsure how to proceed, with each day that passed threatening to permit this aggressive cancer to metastasize further. By the time Southern chose the Cancer Institute team for her care, the cancer was on the move. "It was in my lymph nodes," she says. "In just a few weeks, the cancer had become a lot more pronounced." She received her first round of chemo on December 20, 2012.

For Stage IV breast cancer, neither surgery to remove the tumors nor single drug therapies are generally the way to go. This is the tough stuff to beat, and clinical trials combining new, experimental drugs with the older treatment options hold the most promise for success. "What we offer a patient like Malaya is access to specific trials for her subtype of breast cancer. This is a paradigm shift in treatment from a 'one size fits all' approach to a more strategic and targeted approach that defines precision—or personalized—medicine. We determine the unique molecular fingerprint of a tumor, the unique characteristics of this cancer, with the goal of identifying 'drug-gable' targets," Dr. Toppmeyer explains.

"We're investigating how the cancer cell outsmarts the chemo [develops resistance or escape routes] and how we can set up roadblocks to cut off its exit strategies for survival," she continues. "This is achieved through the design of combination regimens targeting

multiple pathways with established and novel therapeutics."

Eight weeks into the first clinical trial combining chemotherapeutics doxorubicin and carboplatin with the anti-angiogenic drug bevacizumab to shrink the blood vessels feeding the tumors, Southern's follow-up scans delivered good news: the tumors were shrinking.

Targeted Therapy

Precision—or personalized medicine—is just what it says: the therapies target the unique qualities of an individual's cancer rather than the site of origin or the organ type. It's personal.

"We look at the distinct molecular characteristics of the tumor, irrespective of the organs involved. We are after the tumor's unique molecular fingerprint," says Rutgers Cancer Institute of New Jersey Chief Medical Officer and breast oncologist **Deborah L. Toppmeyer, MD**. "We ask: 'what can we uniquely target that will give us the upper hand with this particular cancer?' "As a National Cancer Institute-designated Comprehensive Cancer Center, the Cancer Institute of New Jersey does the research behind new therapies and approaches, as well as offering the newest treatments to its patients.



"We are getting a better understanding of the drivers of the disease, which allows us to develop new drugs to address the pathways involved in tumor cell growth," says Dr. Toppmeyer.

This is the oncologist's advice for anyone faced with a situation like Malaya Southern's: get a second opinion, maybe even a third; explore clinical trial opportunities, since the standard drugs will always be there, but the drugs not currently on the market (but offered in clinical trials) may make a difference in your treatment; go to an NCI-designated Comprehensive Cancer Center, where you will get cutting edge treatment and the availability of clinical trials, many not available at other local cancer treatment sites; focus on living with your cancer.

"We're entering into exciting times. This is a new era of medicine," Toppmeyer states. "Basic science research is moving faster. Gene sequencing is allowing us to develop more therapeutic options, and providing us with answers as we look at tumors to identify even more areas for drug development. We hope that one day we will cure Stage IV breast cancer, even prevent it. That can only be done through research. For now, personalized medicine is allowing us the chance to offer more treatments that will let you live with your disease." ■

But the results of the second round of scans—eight weeks later—were alarming: additional lymph nodes were now involved and the cancer had jumped to the other breast. “There is a positive in all this,” Southern comments wryly. “The doctors were able to get a better biopsy. The original tumor had more scattered cells; it was not a mass. The new one was a real mass.”

The treatment team quickly switched gears. “As long as the patient is responding, we keep them in the clinical trial,” says Toppmeyer. Southern was taken out of that trial because of the cancer’s progression and entered into a new clinical trial after the washout period ended around Memorial Day, when her body was completely rid of the initial drugs. The first restaging scans for this clinical trial, combining Taxol and carboplatin with the anti-angiogenic drug pazopanib, were heartening: “Everything shrank or stayed the same,” Southern says. There were no new metastases.

“Malaya will remain in this clinical trial as long as the drugs are ef-

fective by keeping her cancer in check,” says Toppmeyer. “If, or when, they no longer work, we have other treatment options. Several of the clinical trials combine chemotherapy and biologics to cut-off the pathways the cancer cells need to travel and grow. We are developing treatment strategies for people to live with cancer. Ultimately, we need to develop interventions that will prevent the disease.”

In the meantime, the pain that sent Southern into the emergency room has vanished. “As soon as I started treatment, my pain began to go away.” What she does have is some “collateral damage,” including high blood pressure and hypothyroidism, which she hopes are temporary.

Going the Distance

Southern is not a whiner. She’s running “the marathon,” as she calls it, but everyone in her life is running closely by her side. She has known her husband Sean Kelly since the age of 14. They got

LIFE Hero

Earlier this year, Malaya Southern was honored by the Val Skinner Foundation as a “LIFE Hero.” Spearheaded by **Val Skinner**, a Ladies Professional Golf Association (LPGA) veteran, the LIFE

(LPGA Pros In the Fight to Eradicate breast cancer) initiative was designed to educate young women about breast cancer and that prevention and early detection are paramount. The effort—now 14-years strong—led to the development of the LIFE Center at Rutgers Cancer Institute of New Jersey, which is dedicated to the LIFE mission and is supported in part through the annual LIFE charity golf outing. Since its inception, the event has resulted in more than \$4 million in support of LIFE Center programs. Each year, the LIFE event honors individuals who have demonstrated courage in the face of breast cancer.

“LIFE Heroes symbolize the stories of millions who are impacted by breast cancer. Malaya’s story reminds us how much work there is left to be done,” said Skinner. “The LIFE Heroes we honor serve as our inspiration to continue a passionate fight against a disease that touches so many.” One way to do that, according to Skinner, is through breast education programs, genetic counseling and risk assessment opportunities offered through the



LIFE Center. Included are BioCONNECT—a high school biology curriculum supplement and teacher professional development program—and BOLD—a summer learning opportunity for high school students examining cancer genetics.

But as Skinner points out, education is only half the battle. Research is also vital. Along with support for the LIFE Center, the Val Skinner Foundation has given \$50,000 for laboratory equipment helping advance the latest cancer discoveries, as well as \$100,000 to support the Cancer Institute’s precision medicine efforts, where genomic analysis is helping to identify more targeted treatments.

Skinner sends special thanks to 2013 LIFE event supporters including LIFE Partners: Amy & Joe Perella, Marsh USA, Ed Herilhy, Sandler Oneil Partners, Ken Langone, Guy Carpenter & Company, Atlantic City Electric, C.R. Bard, Emblem Health and Genentech. Other notable supporters are Assured Guaranty, ACE Group, QualCare, The Cox Classic/Steven A. Cox Foundation and Lincoln. ■

Val Skinner (first row, center) and participants of the 2013 LIFE Event.



engaged two weeks before her diagnosis, married at home in their pajamas on December 29, 2012, and celebrated their wedding with friends and family on June 20, 2013. It was everything they had imagined, including the honeymoon, and all of it was planned around her treatments.

Southern proudly shows me a wedding photo—she looks radiant and beautiful and happy. Under her natural-looking wig is the hairless head that Kelly shaved for her when her hair started dropping in clumps.

This woman has guts; she's running that marathon bravely and proudly, and telling her story to anyone who is interested in listening. (Access her blog *Hip Checking Cancer* at: slamourdoll.blogspot.com.) Perhaps it will help them get through their own cancer-challenge; perhaps it will inspire them to fund breast cancer research, giving her and others a better chance to live; perhaps it will paint a new picture of a breast cancer patient that you will never be able to forget.

Despite her statements that she has no particular talent for writing, she truly tells her own story best. So, I end this article with an excerpt from her email to me on the morning after we met because it says it all so well. ■

It was great to meet you yesterday.

I apologize that towards the end of our conversation I was entering into a medication fog and may not have been as clear thinking. On that note, I would like to add a couple of things.

For those patients diagnosed with a "treatable" form of cancer—early stage patients who are given an approximate start and end date—the journey takes on a different perspective than those of us at Stage IV. Many of these early stage patients find that in the end they have found cancer to be a blessing for them. It caused them to slow down, to appreciate life, to do the things they've been meaning to do, to reach out and help others. I think this is an absolutely beautiful thing and a worthy perspective for them to have in the face of such a difficult obstacle to overcome. I would say this would be a goal for any early stage patient. Enjoy the new perspective, embrace it, become the wonderful person you were meant to be.

Now for those of us on the never-ending marathon of Stage IV cancer: our perspective is totally different. Please don't look me in the eye and say cancer is a blessing. There is nothing about a Stage IV cancer diagnosis at the age of 32 that is a blessing. There are some similarities—I appreciate, more than ever, the blue sky, the green leaves on the trees, the air we breathe, my friends and family, every blessing in my life. I am however faced daily that when asked the question (sometimes to myself), when are you done with chemo? The answer is never. This can be daunting. How do I plan? Can I plan? How long do I have? Will they find a new treatment before it is too late for me? There is always a delicate balance between acceptance and fighting. You want to fight for your life and your health and each and every day; however, you do need to find acceptance in the situation you have been given. I take every day as it comes and appreciate it for what it is. I connect with those I love. I keep a positive attitude (though we all have bad days and that's okay too). I look at the chemo as my medicine, my cure. I try to never think a bad word about it. I appreciate each and every doctor, nurse, pharmacist, social worker, nutritionist and staff member at the Cancer Institute. I could never do their job and yet there they are each and every day with smiles on their faces, helping me, making this easier on me. I don't doubt that many of them have their own stories as to why they do this.

Ok, I am off to work now. Have a great day!

Malaya