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The Making of a Metastatic Breast Cancer Advocate

When ob-gyn Kelly Shanahan was diagnosed with metastatic breast cancer in 2013, her passion and expertise fueled a new mission.

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If you’re fortunate, work is more than what you do. It’s your calling. That’s how Kelly Shanahan, MD, 61, felt about delivering babies and performing gynecological surgery as an ob-gyn in South Lake Tahoe, California. She moved there in 1994 to join an ob-gyn practice; in short order, she got married, had a daughter (in 1998) and built a thriving solo practice.

Kelly Shanahan and her daughterLauren Casto

But doctoring was not to remain Shanahan’s profession; cancer saw to that. She was diagnosed with Stage II breast cancer in 2008 after a mammogram revealed a malignancy in one of her “fibrocystic, lumpy-bumpy breasts,” she says. The diagnosis didn’t shock her, as she has a strong family history of breast cancer—her mother and two aunts as well as other relatives had been diagnosed with the disease. But when she and a radiologist reviewed her previous film, she was surprised to learn that a colleague had missed the cancer on a mammogram two years earlier.

Shanahan opted for a bilateral mastectomy, implant reconstruction and four months of IV chemotherapy. South Lake Tahoe doesn’t have any oncology services or radiation therapy, so if she’d opted for a lumpectomy and radiation, it would have meant seven weeks of long drives for a few minutes of radiation. Being a busy mom influenced her decision; she would drive her 9-year-old to soccer practice, among other activities, and was the primary family breadwinner (her husband is a general contractor, but, as a doctor, she was earning more). “I was back in my office seeing patients within two weeks of surgery,” she says. “I scheduled chemo at the end of the week, so I felt crappy over the weekend, and I was back seeing patients on Monday. I was like, I’m putting cancer behind me. It’s just a bump in the road.” Her practice and family life thrived.

Breast Cancer, Round Two

To prevent recurrence, Shanahan went on an aromatase inhibitor. But she developed “really bad arthritis-type side effects” in her hands, so she went off it within a year.

Kelly Shanahan with her oncologist, UCSF’s Hope Rugo, MD, an MBC expertCourtesy of Kelly Shanahan

“The oncologist told me, ‘We don’t need any follow-up. Just report any symptoms.’ Well, five years later, I developed back pain. I sneezed while walking up the stairs and thought I’d pulled a muscle,” she recalls. But it didn’t get better, and an oncologist colleague convinced her that, given her cancer history, she should get scans.

So in November 2013, on her 53rd birthday, she had both MRI and PET scans, “and lo and behold, I had metastases in every bone in my body.” She had already broken a vertebra—hence her back pain—and her thigh bone was perilously close to breaking. The day after she was diagnosed with metastatic breast cancer (MBC), she recalls, “was the last day I picked up a scalpel, the last day I did surgery.” Six days later, she had a titanium rod inserted in her thigh to keep her leg from breaking.

Within hours of her diagnosis, Shanahan was in her oncologist’s office to discuss her prognosis and treatments. She had discovered that the median life expectancy for people with MBC was not quite three years then, maybe not enough time to see her daughter graduate from high school or help her move into her first college dorm, Shanahan recalls now, with a catch in her voice.

But her oncologist imparted a crucial message, saying, “I know you know the statistics. You are not a statistic.” That reinforced her resolve to confront the cancer head-on. “I’ve never been average, ever in my entire life, and, you know, I’m not going to start now,” she recalls thinking.

Life-extending targeted therapies known as CDK4/6 inhibitors had not yet been approved, and, although she might have been a candidate for a clinical trial, Shanahan didn’t relish the idea of frequent seven- to eight-hour round-trip drives to San Francisco during winter in snow country, with a painful rod in her leg. Plus, her oncologist claimed it was a last resort she didn’t need. (She now regrets this decision.)

So she did a “very, very unconventional combination IV chemo—two drugs at a time, two different sets of drugs over 14 months”—followed by a different aromatase. The regimen was successful but left Shanahan with permanent neuropathy in her feet and hands. The numbness made it unsafe for her to continue to see patients. “I might not be able to feel their breast lump,” she explains, “and I might not be able to catch a baby.” In early 2016, she quit practicing medicine.

From Doctor to Advocate

Shanahan’s daughter headed off to college. With an empty nest and her doctoring days over, Shanahan felt adrift. South Lake Tahoe “didn’t have a breast cancer support group until another breast cancer patient and I started one,” she says. She found Facebook groups, attended patient conferences, connected with others who had MBC and volunteered with advocacy organizations. “I found my circle of people,” she says.

Daughter Hunter Turney, musician Ed Sheeran and Kelly Shanahan at a Do It For The Love foundation event in 2015Courtesy of Kelly Shanahan

Shanahan volunteered for METAvivor—an organization that funds MBC research, raises awareness and supports people with the disease—and became a board member in 2019. She started attending professional meetings, including the international San Antonio Breast Cancer Symposium and the annual meeting of the American Society of Clinical Oncology (ASCO), the world’s largest cancer conference. “I’d just walk up to researchers at the end of their talks and ask them questions,” she recalls. She was finding her voice as a cancer research advocate. She joined Twitter to tweet out conference news.

At one ASCO meeting, she walked up to Tatiana Prowell, MD, an oncologist at the Johns Hopkins Kimmel Comprehensive Cancer Center who serves as a breast cancer scientific liaison to the Food and Drug Administration (FDA). They started working together, and Shanahan became an important impetus in the FDA’s push for decentralized clinical trials—“bringing the trial to the people,” she says. When people with cancer can get lab work or imaging tests done locally, for example, it lowers a barrier to participation in clinical trials and can increase the pool—especially among diverse, underrepresented groups—which can help fill studies faster and speed results (see “Easier Clinical Trials”).

Duke University oncologist Nicole Kuderer, MD, Kelly Shanahan, Julia Maués and Christine Hodgdon at the first GRASP session in 2019Courtesy of Kelly Shanahan

“Advocacy keeps me occupied, gives me a purpose,” says Shanahan. “I feel as fulfilled as I did as a physician.”

Shanahan became a mentor for GRASP (Guiding Researchers and Advocates to Scientific Partnerships), an organization started by Julia Maués and Christine Hodgdon, two friends who both have MBC, to connect advocates and cancer researchers. While being a doctor helps open some advocacy doors for Shanahan, Maués says, “when she ‘gets in’ she makes the other side realize that she’s there as a patient, with experience in living with MBC, not as an ob-gyn. Her knowledge, passion and personal connection have elevated her as one of the main voices in MBC research advocacy.”

Hodgdon concurs. “It’s hard to be an advocate because it’s a lot of losses—physical losses as well as losing friends—and not a lot of wins. But Kelly has been able to channel everything she learned as a doctor to be a really, really successful advocate. She’s helped drive positive change in clinical trial design and research projects.”

And she’s done it with almost no financial support. “Most of us who do advocacy, we’re not paid,” Shanahan says. She was fortunate to have received good advice early in her career to get not only life insurance but also long-term disability insurance, “and that pays the bills.” In her first year of conference attendance, she spent $10,000 out of her own pocket. She’s gotten small travel grants for conferences and recently received a small honorarium for a virtual cancer presentation. “It pays for the coffee shop bills and the occasional bottle of wine,” she says, “but not much more than that.”

What People With MBC Need

When Shanahan is asked about how advocacy can move the needle for people with MBC, the first item she mentions is MBC-focused research. Despite the huge levels of funding for breast cancer research, “only 5% to 10% goes toward research that will help people who are actually dying of breast cancer,” she says. “I’m incredibly proud that in 2020, in the midst of the COVID pandemic, METAvivor raised $4.4 million in new research funding, while very large, very pink organizations chose not to fund new research.” In 2021, METAvivor raised over $5 million.

Next is bringing the patient voice into the conversation with researchers. “I’ve been a research advocate on projects where they’re proposing a clinical trial and they want to do all these biopsies. And I’m like, ‘Why? Would you let somebody stick a needle in your liver every week?’” With scientists doing basic research, she’ll say, “This sounds like super cool science, but how’s this gonna help a human being?”

Then there’s legislation. METAvivor members advocate for MBC with their elected representatives in Washington, DC. One bill, introduced in the House of Representatives in May 2021, that Shanahan hopes to see passed is the Metastatic Breast Cancer Access to Care Act, which would eliminate the current five-month waiting period for Social Security Disability Insurance benefits and the additional 24-month waiting period for Medicare coverage for people with MBC. She herself would have benefited from such a law. “I was self-employed, so I didn’t have some big group insurance plan,” she says. “If I hadn’t had some savings, if I hadn’t had a long-term disability policy, I don’t know what we would have done.”

Defying the Odds

Shanahan has outlived the statistics: It’s been almost nine years since her MBC diagnosis. For six of those years, she was stable, with no evidence of active disease, on the aromatase inhibitor. That changed last year, when her mother died of COVID on the East Coast and Shanahan had no chance to say goodbye in person—her oncologist strongly advised against travel. The stress, she believes, suppressed her immune system and reactivated her tumors. She went on a CDK4/6 inhibitor along with an estrogen blocker. This time, she had a liquid biopsy and knows her mutations. “I’m doing great now,” she says.

Currently, she’s planning travel, planning to see people, planning to do things because, “you know, you can’t take it with you,” she says. She recently returned from a long-delayed trip to Europe with a friend with MBC; her husband encouraged her to make it happen. Next, she wants to go to the Galapagos Islands with her daughter.

“I did not choose to get breast cancer, and I certainly did not choose to get metastatic breast cancer," she says. "But every day, I get to choose how I deal with it. And I choose to deal with it with sarcasm and to live my life to the fullest. I always say, 'I am living with breast cancer.' And when I get that tilted head, pitying 'How are you?' my answer is a very perky, 'Not dead yet!' which makes a lot of people uncomfortable—I don't really care.

"I will continue to try to make a difference, to fight for research funding and for laws for health equity. I will continue to remind people that those of us living with metastatic breast cancer and the 44,000 of us who die from it every year in the U.S., we deserve better," she says. "And hopefully, I'll leave this world a slightly better place than when I entered it."

Anyone Can Be an Advocate

Kelly Shanahan believes there's a place for everyone in advocacy. "The first time you ask your doctor, 'Why are you recommending this?' you are being an advocate for yourself," she says. You just have to think about what comes naturally to you and what you like doing. "If you were that person who ran for town council, legislative advocacy can be your place. If you are always asking why and you're interested in figuring things out, research advocacy might be right. Are you a computer geek? Many organizations could use some help with web design. If you are the PTA mom or dad and you did all the fundraisers, there's a place for you in raising money for all sorts of things—support, research and more."
