

Becoming an Advocate: The Power of One

BY KATHY LATOUR

In addition to the estimated 8,000 medical professionals and researchers in San Antonio this week, there will be 181 men and women who registered as advocates. These individuals may be part of nonprofit organizations that provide services for patients across the country—from the 35 advocates of the Alamo Breast Cancer Foundation to the women from the Young Survivor Coalition and Her2 Support. Or they may be in San Antonio as individuals, hoping to learn more about breast cancer for their own diagnoses.

Advocating is a relatively new phenomenon. Indeed, advocates will often say that they didn't know what the word meant the first time someone referred to them as one. They just knew they wanted to learn all they could to help themselves, other women, or men with information they felt they did not have; or they wanted to be there for newly-diagnosed women emotionally; or they wanted to help women in their community get better access to treatment; or they wanted to change their state laws about mammography or drive-by mastectomies.

Then all of a sudden, they find themselves in the position that they are speaking up—for themselves, their community, or for their country.

Advocacy: A Voice for Others

Joan Venticinque, who is attending the symposium for the second time on a scholarship from the Alamo Breast Cancer Foundation, volunteers in numerous capacities near her home in California. She sits on the helpline at Breast Cancer Connections in Palo Alto, California, and has served on committees designing survivor care plans and in a number of other capacities.

“Breast cancer is a political disease too,” Venticinque says. “So I have also been to Washington to lobby for more funding.”

Venticinque says she tells women that becoming a cancer advocate starts with advocating for yourself and then for your community. “Start small and learn how to talk to your doctors, and then from there you can reach out to your community and see what it feels like. You may then want to go national.”

For women who are sick or not able to be out and about, Venticinque points to the computer as a way to be an advocate every day. “When women in chemo want to do something, I give them links they can research.”

A Personal Journey

Most of us who have been “doing” cancer for a period of time, came to advocacy accidentally because we wanted to learn or were angry at yet another needless death of a friend. Passion is at the core of all advocates who may have never spoken to a group in their lives before cancer brought out a new perspective of their personality.

Although I am covering the San Antonio Breast Cancer Symposium advocates for *CURE*, my own journey to advocacy has had many interesting turns, one of which occurred in 1993, when I attended the symposium as a new author. My book, *The Breast Cancer Companion*, had just arrived from William Morrow, my publisher in New York City.

Because the book was aimed at breast cancer physicians and women newly diagnosed, I had made a deal with my publisher to give me books instead of doing a book tour. I don't even remember who it was who told me about a meeting of breast cancer physicians and researchers in San Antonio, but I got on the phone and asked the person taking registrations if I could bring my book to sell—and bring a few friends.

The voice on the other end was rather confused because there was no category for us on the registration form at the time. Once it was determined it was OK to bring the books, I asked if we could sit in on the presentations. He said he felt they would be too complicated for a lay person, but I could go to the lunch, where the physicians ask questions about complex cases to an esteemed panel of breast cancer experts.

Fine, I said, sign us up. The four of us loaded up with books and took off for San Antonio.

Beyond the Medical

I don't remember how many books I sold, but I did have a few good conversations with physicians about my passion: the understanding that breast cancer was a dual journey, both medical and emotional. When I was diagnosed in 1986, I got great medical care, but no one addressed my soul and the person who would emerge from the experience.

I had a 1-year-old daughter, Kirtley, when I was diagnosed. I lived with a level of fear, that was almost unbearable for a number of years, that I would not be here to raise her. I wanted cancer doctors to recognize the need for psychosocial support for women, something that was almost unheard of at that time and is now a standard part of care in most places—due in great part to advocates.

Then the second day of the symposium, the four of us attended the luncheon in the Hyatt ballroom. There we were, sitting at a table for 10 and feeling very, well, out of place. Everyone there was a doctor, and the women physicians were few and far between. The doctors sort of glanced our way, wondering who we were,

assuming, I guess, that we were students. None sat down with us.

What happened at that lunch changed my life, and I was introduced to a new concept of what my life would become. I was already active in the Dallas breast cancer community. The four of us were all in a support group in my surgeon's office (the first one in Dallas, which started in 1989). And in 1992, we helped start a nonprofit called The Bridge to assist uninsured women with diagnosis and treatment. We had all been working hard to raise money for The Bridge, but I don't think one of us thought of ourselves as advocates.

At one point in the lunch, the physicians were invited to go to a floor microphone and offer a question to a panel that included a radiation oncologist, a medical oncologist, and a surgeon. The first case, from a surgeon, had to do with a woman who had presented with malignant lymph nodes, but, the surgeon said, there was no tumor in the breast. The woman wanted to have a bilateral mastectomy to be proactive, and the surgeon was trying to figure out what to do.

The surgeon on the panel jumped in and said that the surgeon should use all means to talk her out of removing her breasts because no woman should lose her breasts. He shouldn't do it. This surgeon was a huge proponent of lumpectomy, railing against women doing more surgery than he thought necessary.

But she had three small children, the surgeon countered, and she wanted him to guarantee there was no cancer in her breasts, which he was reluctant to do. Again, the doctor on the panel said, "No way. There is no clinical reason."

All of a sudden my inner voice was screaming. "You can't talk for me. That's my decision." Luckily, I didn't verbalize it, but I found myself ready to do battle for the woman.

I remembered telling my surgeon that I didn't care about my breasts. "Take them off on the kitchen table with a butter knife," is what I think I said. I only wanted to live to raise my daughter. How dare this man say no woman should lose her breasts like she had nothing to say about it. He didn't get it.

I had walked into that luncheon that day a bit reluctantly, feeling like I didn't belong and that I was somehow behind enemy lines. How I wish I had had the courage to go to the microphone and challenge him.

A Friend in Advocacy

With me on that trip was Diana Rowden, a friend since college who had shared many an adventure with me while we were roommates in Spain and in Washington, D.C. after college. We both ultimately found ways to get back to Dallas where we both married and settled down.

Then we were both diagnosed with breast cancer. Diana had been an integral part of The Bridge's board of directors and was volunteering for Susan G. Komen for the Cure, whose national office is in Dallas. When we returned to Dallas from the symposium in 1993, Diana became more active as a volunteer with Komen, eventually serving as the chair of the board. When we talk about that trip now, what struck her was the complexity of the disease and that even the breast cancer

experts didn't always have a ready answer.

"It was kind of scary as a survivor," Diana recalls thinking today, "yet it motivated me to learn more."

Diana was diagnosed five years after I was and a year before my mother died of metastatic breast cancer. Her mother had died of endometrial cancer. Since then, we have both lost great friends to breast cancer. We have cried, screamed, and railed at this disease.

But we have also celebrated each year together as survivors. Diana was the first one I called when I went through breast cancer again last year. This time it was DCIS, and I caught it early. She called me first when her implant became infected, necessitating its removal. Diana is also my daughter's godmother.

Today Diana Rowden is the Vice President of Health Sciences for Komen. Her advocacy has taken her to a full-time role of serving women across the country by overseeing the most promising research grants that Komen funds.

My advocacy has also taken me to a full-time job of working to educate men and women about cancer with *CURE* magazine. Neither of us had being breast cancer advocates on our list of things to do in our life—but there you are.

My daughter has now graduated from college and is working in New York City. She and Diana have become great friends, and I know that when they get together there is a strength of commitment on Diana's part for Kirtley and all the other young women in the country that will keep her advocating for breast cancer until we have a cure.

She and the other advocates you will read about this week have given over their lives for the greater good of giving voice to those who don't have it. We celebrate their lives and their work.

Read more of *CURE's* coverage of the 31st annual San Antonio Breast Cancer Symposium at <http://media.curetoday.com/html/email/sabcs>.