

Susie Brain – Advocacy in Actions

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Never did I think that I would become a breast cancer "statistic."

In 2004, I was busy channeling my passion for the environment through my work as executive director of a local nonprofit, when I discovered a lump in my breast. Having undergone yearly mammograms for over a decade, I was dumbfounded to receive the diagnosis - invasive breast cancer. I had a lumpectomy and one week after my surgery I returned to work. Hoping to avoid chemotherapy,

I was discouraged when my pathology results revealed that I was HER2-positive and that dose-dense chemotherapy was recommended. (Herceptin® was not approved for early-stage patients until 2005.) The dose-dense regimen was very tough on me. I lost weight from not eating and became very anxious because I could no longer multitask at my job. Radiation followed, and I became extremely fatigued and lethargic. I also developed severe cognitive issues and realized I had to give up my job.

Thankfully, my husband was my "rock" and, along with the support services and workshops offered by Breast Cancer Connections (BCC) in Palo Alto, I slowly regained my health and energy. I attended a wide spectrum of classes - from life coaching to creative dance. I even wrote poetry in a creative writing class. These are activities I would never have pursued before my diagnosis! I began to feel that I wanted to

"make a difference" so I volunteered to be the first point of contact for people who reach out for support through the BCC Helpline. I continue to do this work today and am truly inspired to help the growing number of women without finances, family, caregiver, insurance, or access to health care.

To make sense of my breast cancer diagnosis, I learned as much as I could about the disease, attending conferences in the San Francisco area, where I live. In the spring of 2007, BCC nominated me to be a consumer reviewer for the Department of Defense (DoD) Breast Cancer Research Program (BCRP). I was thrilled to represent my peers and offer the perspective of breast cancer patients. But despite having a science background, I found grant reviews extremely challenging and felt humbled by how little I knew about breast cancer research.

I enjoyed the panel review experience tremendously and appreciated feeling welcomed by the scientists. But I knew that if I wanted to become an effective consumer reviewer and research advocate I would need more science training. Enter the National Breast Cancer Coalition's Project LEAD® training courses. I have graduated from all three: Project LEAD® Institute, Clinical Trials Project LEAD®, and Quality Care Project LEAD®. These training courses led to opportunities for scholarships to attend national conferences including the San Antonio Breast Cancer Symposium and the ASCO Breast Cancer Symposium. I have also been trained through Komen Advocates in Science and the Research Advocacy Network's Advocate Institute.

The highlight of my early advocacy involvement was attending the DoD's Era of Hope Conference in 2008. Held every three years, this conference brings advocates and BCRP-funded researchers together to present updates on their studies, to network, and to form collaborations. I particularly enjoyed the informality of the poster sessions, where I met scientists from the University of California, San Francisco (UCSF) and Stanford University, including Dr. Peter P. Lee. After he spoke about his research on breast cancer and the immune

system, which was supported by an Era of Hope Scholar Award, I gave him my business card and asked him to contact me if he ever wanted to work with a local consumer advocate. Little did I know that in 2011, I would serve as a consumer advocate on his successfully funded Multi-Team Award and be named on his poster at the 2011 Era of Hope Conference! Yes, Dr. Lee had kept my card.

Over the years I have worked hard to become a respected and trusted advocate. In addition to the extensive hours of direct client support I provide at BCC, I work diligently to introduce advocacy opportunities to BCC clients through my role as chair of BCC's survivorship and advocacy task force. I lead a group of trained advocates who provide input and the patient's perspective to scientists who are applying for research grants.

As more funding mechanisms require advocate involvement, I have taken the opportunity to expand our role as advocates. We help with grant development and review and if the grant is awarded we make sure that we continue our involvement. For the past three years I have worked to nurture a "win-win" partnership with a Stanford research pathologist. While our task force has helped him win grants, he has taught us about his research, introduced us to his team, and given us a tour of his lab. We engage in meaningful discussions about his research, barriers to progress in cancer research, bioethics, and more.

I have taken a leadership role in representing patient interests locally and nationally. As a policy advocate with a strong conviction to better the circumstances of those dealing with cancer, I have attended legislative advocacy trainings and lobbied with the Environmental Health Legislative Working Group and Susan G. Komen for the Cure®, the National Breast Cancer Coalition, Lance Armstrong Foundation, and One Voice Against Cancer.

Since 2007, I have been a member of the Cancer Patient Advisory Council at the Palo Alto Medical Foundation (PAMF), interacting with clinicians to support the efforts of the Cancer Care Focus on Living

program. I felt especially valued as an advocate when I was invited to sit on the Stanford University Cancer Center's scientific review committee. This committee, comprised of eminent clinicians and scientists, provides peer review of local, national, and international research studies. When I accepted an invitation from the director of the Stanford Cancer Center to join their survivorship program working group, it occurred to me that I was no longer having a problem multitasking!

As an active member of the NCI-funded Breast Cancer SPORE at UCSF I helped plan our recent annual advocacy retreat. I relish the opportunity to learn about late-breaking breast cancer research results at the weekly sessions of the UCSF breast oncology program and be involved in unique science collaborations there.

I know that I am fortunate to be able to volunteer full time and stay informed about the latest breast cancer research, survivorship, and advocacy issues. I enjoy mentoring, networking, and collaborating with both advocates and scientists and hope that my story will inspire others to develop professional and collaborative relationships in their communities. If we work together we can positively impact the lives of future patients and be in a position to support major breakthroughs in breast cancer research. Let's start now by ordering those business cards!.

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