

CONNECTIONS

Why I Wanted My Tumor Back

BY DIANE BALMA, JD

I was a well-educated, sophisticated, professional, 30-year-old woman about to undergo surgery to remove a 3-plus-centimeter tumor from my breast. I was medically naïve, uninformed, and anxious. I did not ask before signing the surgical informed consent what would happen to my tumor once it was removed. Rather, I was preoccupied with whether I would lose my breast or, more profoundly, whether I would live to be 31.

It wasn't until several years later, while in my office at Susan G. Komen for the Cure, reading up on tumor tissue preservation, retention, and tracking (that is, what happens to a tumor after surgery), that it dawned on me: My cancer—the very thing that nearly killed me at such a young age—could one day hold the key to new targeted therapies that might save my life.

When I was diagnosed in 1995 with an aggressive form of breast cancer, physicians had few reliable measures of medical aggression. Pathology testing for HER2, an important factor in assessing odds of survival, was not always accurate. My initial pathology report was negative for HER2. Within a few years, however, my tumor, which at the time fortunately was still “on file,” was re-tested. The result was quite different.

Not only did I have HER2 breast cancer but, in the words of my doctor, the result was “off-the-charts positive” in every single tumor cell tested. Worse, I learned that the type of chemotherapy I received was not very effective with my type of breast cancer.

I flashed back to my treatment days when I was so sick from the chemotherapy that I had to crawl to the bathroom, where I would lie on the floor for hours. The same bathroom that my precious grandmother and caretaker would scour every morning so that I would not notice how much hair I had lost the previous day. I never stopped wondering whether her suffering at seeing me so ill would be in vain.

But I also learned that my type of cancer was responsive to a new, targeted drug, and that I would be a candidate for the drug if my breast cancer recurred.

As I read about the lack of uniform national standards regulating tissue retention and preservation, I was overcome by a powerful uncertainty: Did my tumor specimen still exist? If it was no longer preserved and accessible, it could never again be tested to determine whether I could benefit from new breast cancer therapies, or even a cure. I was panic-stricken. Had my tumor tissue been thrown out? If not, where was it, and how could I find it?

I had waived any rights I might have had to my tumor specimen when I signed the presurgical informed consent forms. Even if the requirement to sign the consent forms to have the lifesaving surgery constituted duress (a legal argument that could make the forms invalid), I had virtually no rights to my specimen anyway.

Nevertheless, I decided to track down my tumor. I called the community hospital where I had undergone the lumpectomy. No tumor. I then called the comprehensive cancer center in San Francisco where my mastectomy was performed. No tumor. In an act of desperation, I called the community hospital back, told them that I was a lawyer and worked for Komen, that I was not crazy, but that I wanted my tumor back.

The FedEx package arrived at my office two days later. In it was a box that held my tumor in all of its paraffin glory. For a week or two, I couldn't stop looking at it. For more than a year, I kept my tumor in my office in the same box in which it arrived. To avoid paraffin melt in the Texas heat, I waited until winter before driving it home. My tumor continues to reside in its box, in my closet, next to my shoes.

I want something better for cancer survivors. So does Susan G. Komen for the Cure. That's why we are taking a leadership role in proposing uniform national standards for tissue handling, preservation and access. This is an issue that has major implications for hundreds of thousands of patients yet to be and those already diagnosed with breast and other cancers.

Komen proposes to achieve the right balance between ensuring that patients have ready access to information from their specimens for clinical use, and the academic community has access to tissue for research. These are complex issues with numerous conflicting stakeholder interests. Tissue banking that doesn't occur in a responsible manner is another obstacle standing in the way of the cures. Komen promises to resolve this issue, just as we promise to end breast cancer forever.