



Remembering the People Behind the Data

BY JOAN VENTICINQUE

Joan Venticinque was awarded a scholarship by the Alamo Breast Cancer Foundation for the second year to serve as an advocate. In this role, she has agreed to blog for CURE to keep you up-to-date from an advocate's perspective. To learn more about Venticinque and her role as an advocate, read ["Full-Time Advocate."](#)

Day three of the SABCS brought many presentations on HER2 research. Scientists are looking at the many pathways that target the cell signaling in tumors that overexpress HER2. I think our HER2 sisters can feel like the future will bring many therapies for them.

During the mentoring session Thursday night, one of the doctors made the comment that we could have a great drinking game if we took a shot every time we heard the words "targeted therapy." It was a good joke, but true. I'm very excited to hear that so much research is heading to the individualization of therapy based upon the biomarkers of tumors.

During one of the presentations, Barbara Brenner, executive director of Breast Cancer Action, came to the microphone to make what, I believe, was an important comment from the advocate point of view. She commented, "Please don't refer to patients having 'failed' treatment, but refer to the treatment having 'failed' the patient." A doctor answered, "Very good point," then went on to take the next question, in which the presenter stated, "Some women had a good performance status ..."

I know this might be splitting hairs for some very busy doctors and researchers, but I think they need to be sensitive to the fact that we have little, if no control, on how our bodies respond to therapies. I know data is just the cold hard facts, but please remember there are mothers, sisters, and daughters behind those facts, and we are warm, living, and breathing people. As patients, we cannot tell you how much we appreciate the research you do, but would it be so hard to change a few words around?

—Published 12.13.08

Examining Treatment Options and Side Effects

There's excitement in the air (and a little more warmth) as more attendees descend on the Henry B. Gonzalez Convention Center and the sessions begin.

This morning's presentations concentrated on the use of hormonal therapy as adjuvant therapy for estrogen positive breast cancer. This is a topic of great interest to many of us advocates as we are taking these drugs and living with the side effects.

There were reports from many trials: BIG 1-98, TEAM trial, and the ABCSG 8. The trials compared tamoxifen versus one of three aromatase inhibitors (exemestane, letrozole, and anastrozole) used alone or in a sequencing strategy.

All trials agreed that aromatase inhibitors have significant benefit to tamoxifen, either treating upfront with an AI or switching after tamoxifen. One would think these studies would be the answer to the question of what hormonal therapy to use, but nothing is that simple.

Many doctors came to the microphone asking the researchers if they would recommend AI exclusively for their patients. The answers ranged from "a very high trend toward recommending an AI" to the "need to balance the efficacy gain with the tolerability of the patient" to "low-risk patients should be started with tamoxifen then switched to an AI."

I believe this meeting will have more doctors using an AI upfront. As a patient advocate, I still have one question that hasn't been answered yet: What about the issue of long-term therapy with AIs over five years? Maybe next year's SABCS will answer that question.

This afternoon's presentations continued the subject of using endocrine therapy for breast cancer.

There was an interesting presentation done by the Dutch TEAM trial researchers on the quality of life in relation to hormonal treatment of postmenopausal women using either exemestane or tamoxifen. The researchers looked at 2,754 postmenopausal early breast cancer patients who were randomized between five years of exemestane or around 2.5 years of tamoxifen followed by around 2.5 years of exemestane. Patients were asked to fill out questionnaires at one and two years after the start of treatment.

There were no significant differences in physical, cognitive, or emotional functioning, body image, breast or arm symptoms, or endocrine symptoms between both treatment groups at both year one and two. Patients receiving exemestane had significantly less sexual enjoyment and more insomnia at year one when compared to the tamoxifen group. At year two, the exemestane patients reported significantly worse sexual functioning and still more insomnia.

These side effects are well-known and talked about in support groups all over the world. These drugs affect our bodies and our relationships. We as advocates need to ask the researchers to study safe and effective treatments for these sexual side effects so we don't have to tell our partners, "Honey, I'm sorry, I'm just too tired, and it hurts too much."

—*Published 12.11.08*

Advocates Face Many Choices in Era of Personalized Medicine

Greetings from cold San Antonio, Texas. How it can go from 82 degrees to sleet and snow in a matter of hours chills my California bones, but the warm welcome I

received from the Alamo Breast Cancer Foundation (www.alamobreastcancer.org), as a member of the Patient Advocate Program, made up for the cold.

In anticipation of all the science I will need to absorb this week, I attended the National Breast Cancer Coalition's (www.stopbreastcancer.org) Advanced Topics class this morning. We learned about the role of signaling pathways in cells and how these pathways contribute to the complexity in the development of cancer.

We also had a presentation on epigenetics, the study of changes in gene function that occur without a change in the DNA sequence that could occur by mechanisms such as DNA methylation, chromatin organization, acetylation, and phosphorylation. These could be proven targets for therapy.

There are current clinical trials for therapeutic intervention in certain blood cancers, and scientists are now starting to study ways they can exploit epigenetics for the treatment of solid tumors.

It is obvious from my first few hours here in San Antonio that the era of personalized medicine is the treatment of the future. For us advocates, especially those of us who sit on grant review committees, the question is how do we determine which road to choose for funding? Do we concentrate on the causes of breast cancer, prevention, and treatment? What about using genetics to further classify tumor type and to develop targeted therapies? The answer seems obvious; we need to go down all the roads, with all their twists and turns, ups and downs.

I know that over the next four days, I'll probably learn more than I can take in. But I will meet dedicated doctors, researchers, and scientists who are working long hours so that I can live a full life, despite my cancer diagnosis.

For more information on epigenetics, check out the feature "Medicine's New Epicenter? Epigenetics" in the upcoming Winter 2008 issue of CURE.

—Published 12.10.08

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