

The gift of self: Becoming a medical guinea pig brings rewards

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By Eileen Beal

In 1995, as suggested for us “women of a certain age,” I started getting a mammogram every year.

Each spring, my HMO—Kaiser—would send a post card reminding me to call and set up an appointment. I’d call. I’d go in for the mammogram. A week or ten days later they’d send a letter: Dear Ms. Beal, Everything’s fine. See you next year.

That was the drill until 2001. That year, the radiologist’s assistant called. My X-rays had turned up white dots—microcalcifications, she called them—in my right breast. It wasn’t cancer, she stressed, but it could be a pre-cancerous condition and I needed to come in for a consult.

After seeing my X-ray and talking with the radiologist and a surgeon, I was scheduled for surgery. Ten days later the surgeon removed a tissue core from my breast: It contained the white dots and a half inch or so of the tissue surrounding them “to make sure we got everything,” the surgeon explained.

A follow-up mammogram 6 months later, and all mammograms since, have been fine. The inch-long scar from surgery has almost disappeared.

Still, I’m haunted by those “white dots” because they put me at a significantly increased risk for developing breast cancer.

So, when I went for a check-up in February of 2003 and gynecologist Mark Binstock, who’d noted my brush with breast cancer in my medical records, asked me if I’d be interested in participating in a National Cancer Institute-sponsored trial—the STAR Project—my ears snapped forward.

When he explained what the trial was for—to compare the effectiveness of two drugs, tamoxifen and raloxifene, in reducing the occurrence of breast cancer in postmenopausal women—and that he was having trouble getting women my age to enroll in it, I needed only the span of a heartbeat to say yes.

Being a medical writer, I know the importance of clinical trials.

Each year, hundreds of thousands of people are asked to participate in them. Unfortunately, the number of people who opt to do so is a fraction of those who are asked, especially in my age bracket. Some say it’s too much trouble to participate in a trial where they could be wasting their time with a sugar pill or sham procedure [placebo]; some want to get paid to participate; some don’t like all the government paperwork and medical protocols that come with participating in a trial; some don’t trust scientists and medical researchers; and a few are too scared—or too much in denial—to participate in a trial.

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When people don't participate in trials, everyone suffers. Trials are the best (and sometimes only) means researchers and physicians have for discovering if drugs and procedures that work perfectly in the laboratory will work in the real world, too.

I was nervous about enrolling in the STAR trial—especially after reading the 8-page consent form that began starkly with this statement: You are being asked to take part in this research study because you are at increased risk for developing breast cancer—and committing to taking two pills every day for the next five years of my life. But I knew that becoming a STAR guinea pig—because that's what signing on to the study turned me into—was going to have a huge pay-off.

As the season for giving rolls around I'm reminded anew just what that pay-off is. As a "senior" STAR participant I'm getting to turn the scary hand I was dealt into a gift that will keep on giving: Information, knowledge, and hard data that will be used to change the way breast cancer is treated, and potentially prevented, for women everywhere.