

Why I joined a lymphedema clinical trial

Posted At : October 16, 2009 3:01 PM | Posted By : Kathy LaTour

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I joined a clinical trial this week, but it has nothing to do with a drug or treatment. It's to see whether aquatic (water) exercise will have any effect on my lymphedema, the swelling of my right arm that resulted in an infection I had four years after my first mastectomy in 1986.

Lymphedema remains one of the most difficult late effects of breast cancer because it can show up for no apparent reason, there is no cure, and managing it can be difficult.

My lymphedema occurred as the result of an infection in my arm that was caused by a hang nail. That's right, a hang nail. When I felt the familiar pain in the middle finger of my right hand, it was 1990, four years after my mastectomy. My surgeon had mentioned that I needed to care for my arm after surgery, but, like many women diagnosed with breast cancer, my thoughts were on other issues at the time –such as dying.

So, when, four years after surgery, I had a hang nail, I didn't give it a thought. I ran it under hot water, which was the only thing I had ever done to kill what had always been a mild infection. This time it was different. As my hand and then my arm started to feel strained that day, I never connected it to my surgery or the possibility of lymphedema. But the next morning when my arm was hot, swollen and red, I knew I was in trouble. I called my surgeon, who immediately put me on the nuke of antibiotics and told me to see her first thing the next morning, which was Monday.

By the time we reached her office, the red from the arm had traveled onto the chest wall, and she took one look at it and marched me off to the hospital where I stayed for five days on IV antibiotics.

The result: my right arm is larger than my left, and I had two more infections in the next year. Luckily since then, it's only been the swelling that has been a problem.

Over the years, I have undergone manual lymph drainage, wrapping, and I do self massage when I think about it. Alas, I refuse to wear the sleeve due to the fact that it cuts me, and in Texas in the summer, well, let's just say that I detest it. And after a story we did in *CURE* questioning the effectiveness of the sleeve, I was eager to give it up. I bought a sequential pump that made no difference, and then reverted to the only thing that seemed to work for me to keep the arm at its smallest, which was swimming.

So, when I heard about this clinical trial being conducted by a local breast surgeon, I signed up. In the trial, he is looking at 50 women with "lymphedema secondary to breast cancer."

We all agree to take part in 12 Water Works aquatic exercise classes at the Tom Landry Wellness and Health Center, a beautiful facility close to the hospital where I was treated that has a heated exercise pool and a staff of young, energetic professionals. And there is no charge for the classes that are held in 89 degree water in the shallow pool. The classes are an hour each and include low-impact movements for warm up, stretching, breathing, and upper- and lower-body resistance training. Before the first class, both my arms were measured and I filled out a questionnaire about overall health and wellness. At the end of six classes, I will be measured again, and then again at the end of 12 classes.

Then they will keep me informed about findings for the next five years.

I am hoping it shows some success. I have read research on lymphedema over the years and I know many women suffer with it in ways I don't – not being able to wear sleeves, the heaviness and pain of the arm, constant infections, and the obvious embarrassment of having a large arm.

There are other clinical trials looking at issues related to having had cancer. I want to encourage you to research the trials near your home and take part.

Go to <http://clinicaltrials.gov> and type in search words for your type of cancer and survivorship and look at your options.