

# TIME TO CHANGE THE BREAST CANCER CONVERSATION



By LAURA SNYDER  
For The Daily Astorian

**O**n the cusp of Breast Cancer Awareness Month, I'm grateful for the opportunity to check in.

I'm still above ground, as they say, so that's a plus.

After a year of stability on my first line treatment for my HER2+ metastatic breast cancer (MBC), I abruptly changed treatments because those drugs were no longer effective at keeping my cancer at bay.

This is typical with metastatic patients. Our treatments work until the cancer figures out a way around them, and we have to move on. I have to say, I was hoping for more time on that first, relatively doable regimen.

This is life with mets, for all of the estimated 155,000 people in the U.S. living with this disease.

**E**nough about me though. As I have become a full-time cancer patient and lost my ability to work for a living, I thought I would try to be of use in this, my new normal, my new occupation.

I was privileged and grateful to attend Living Beyond Breast Cancer's Annual Metastatic Breast Cancer Conference this past April. Over 300 of us "metsters" dragged our broken bodies to Philadelphia to participate in breakout sessions and network and be with each other.

Alongside the conference I was fortunate to be accepted into LBBC's first Hear My Voice Advocacy Training, with about 25 other participants.

These included a 24-year-old professional ballerina; a 35-year-old civil rights attorney and mother of young children, who was forced to retire; a 34-year-old former AIDS social worker (also retired), among others, all living with MBC.

It was an amazing experience, culminating with a "die-in" on the floor of the Philadelphia Loews Hotel. 110 of us laid down to show the number of people dying from MBC every day in the United States. There was a eulogy, a somber silence and a sense of the surreal.

And this was where the new organization MET UP ([www.metup.org](http://www.metup.org)) was born. MBC Exchange to Unleash Power is modeled after ACT UP, the AIDS activism group, and has mentored MET UP in the best of ways.

## Writer's Notebook

I'm not sure the organizers of this first training anticipated the scope of the die-in planned in Washington, D.C., for Oct. 13, the day in October dedicated to MBC. 1,430 people will lie down at the Capitol and "die" to symbolize the number of people worldwide that die of MBC every day. Meetings with legislators are scheduled the day of the die-in, to demand that more federal breast cancer research funding go to MBC. We have more than enough awareness. It's time to work for real change and a cure.

**M**any of us across the country not traveling to D.C. are organizing die-ins in our own communities.

I have partnered with Astoria High School senior Libby DiBartolomeo to organize our own local die-in Oct. 13.

This is her senior project and she is full of passion about it. Do anything you can to support her efforts, including attending the die-in at Astoria High School (time to be announced).

I am scheduling meetings with Sens. Ron Wyden and Jeff Merkley and Rep. Suzanne Bonamici's staffers to share with them the realities of MBC and the distinct lack of research funding going to this incurable disease.

Presidential candidate Scott Walker said that the biggest threat to American lives is radical Islamic terrorism. Not true. Heart disease and cancer are actually the biggest threats to American lives. Federal dollars need to go to medical research.

**A**nother of my projects is starting and sustaining a yoga program for MBC patients in our community. Yoga practice has sustained me through very tough times in the last year and a half, and I hope to share it with others in my little boat.

After my diagnosis of metastatic recurrence to liver, lungs and mediastinal lymph nodes, I returned to a regular yoga practice.

Though my prognosis is obviously much worse than the first time, my mindset and physical health are exponentially better. Research is clear that yoga for cancer patients produces a

significant decrease in anxiety, depression, perceived stress and fatigue severity, as well as significant improvement in emotional and cognitive function and global quality of life.

Progress toward this goal is slower than I'd like, but progress is being made toward making this free program a reality.

**D**ue to the "pinkwashing" of breast cancer, especially in October, many people are not aware that breast cancer is not the "easy, curable cancer" it has been portrayed as by organizations like Susan G. Komen for the Cure and others.

Many are not aware that up to 30 percent of early stage breast cancer patients will have a metastatic recurrence, at which point the disease becomes incurable. Up to 30 percent!

Unfortunately these numbers are extrapolated from early stage diagnosis numbers and mortality statistics, as SEER (Surveillance, Epidemiology and End Results) and most state cancer registries do not track metastatic recurrence at all.

As my friend Beth pointed out so succinctly in a blog post, "If all you want to do is to say 'Hey you, there is a thing and it is called breast cancer' then yes, awareness is the right tool." Why would we want only that? We don't need cute pictures of dogs in bras. (For real. Check the Komen website.)

We need education and we need money for research for a cure.

**I** hope to change the paradigm of breast cancer awareness in our community to one of action and focus on the things that matter, like scientific research to find a cure and treatments less toxic to prolong life and enhance quality of life.

Let's maybe stop buying pink trinkets and registering for races. Money raised this way does NOT go to research to find a cure.

Susan Komen died of metastatic breast cancer, causing her sister to found Komen to raise more awareness of breast cancer. It was well intentioned and a wonderful cause at the time. However, it has become clear that the corporate partnering and marketing of stuff has taken the front burner at this and other breast cancer charities.

I'll say it one more time. We are all aware of breast cancer. It's time to change the conversation to curing it.

*Laura Snyder sold her Astoria bookstore, Lucy's Books, in 2011 after 13 years of business.*

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Submitted

A recent Susan G. Komen "awareness" post.



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