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Erick Bengel | Features Editor
ebengel@dailyastorian.com

WEEKEND BREAK

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There's much more at stake than being aware

Three years with metastatic breast cancer: My annual report

By **LAURA SNYDER**
For EO Media Group

'So it was that for two minutes we sang with all our hearts, feeling only for the past and turning our gaze from the future, swimmers doing the backstroke toward a waterfall."

— Viet Thanh Nguyen, "The Sympathizer"

Astrophysicist Neil deGrasse Tyson said, "The good thing about science is that it's true whether or not you believe in it."

You know, like the scientific fact that the climate is changing, or the fact that a fraction of the dollars (estimates are 5 to 7 percent) for cancer research addresses metastatic cancer.

Yes, there have been game-changers in the metastatic cancer area, especially for those with the HER2 positive subtype of breast cancer, some leukemias and some lung cancers.

But many friends and I are living on borrowed time. The refusal of some people, including in our government, to acknowledge science is personal to me and my family, as I have metastatic (stage IV) breast cancer (MBC).

The short version: After a stage III breast cancer diagnosis in 2012 came a shocking metastatic diagnosis in 2014. The cancer had found its way into other parts of my body. Three and a half years later, thanks to science, I'm here, past my three-year median survival expiration date.

I'm so grateful for my life: running; swimming; writing; practicing yoga; spending time with loved ones; eating the bounty of my chosen home (salmon, crab and oysters, blackberries and homegrown strawberries). It's all much better than the alternative, right?

What does this mean for me personally? Starting in 2012, I have been on six different chemotherapies and targeted treatments, and/or radiation for all but nine months through 2013 and 2014. I will never, as long as I manage to live, be off treatment.

But if I really dig, what does it mean?



Laura Snyder

Submitted Photo



Submitted Photo

It means I'm exhausted, all day, every day. And that is with the "easy" chemo I'm on now. For now, I do not have excruciatingly painful peeling feet and hands, nausea or vomiting, just to name a handful of side effects I've experienced on other treatments. I do have blurred vision, dry eyes (this can actually be torturous), dizziness and the occasional bout with vertigo.

This is not the exhaustion of a brutally hard work day. The exhaustion I have is far beyond any "tired" I've experienced in my life. Cancer treatment fatigue is its own cruel type.

Awareness is not enough

So we arrive at another October, Breast Cancer Awareness Month.

Not much has changed in the 30 years since the introduction of the pink ribbon. And I, for one, am never glad to witness another month of a world turned pink to bring "awareness" to an awful disease of which we are already so very much aware.

Awareness is not going to cure me, or turn my terminal disease into a chronic and livable disease. Awareness will not cure my large community of those with MBC. What may possibly net us a cure, or turn stage IV breast cancer into a chronic and livable disease? A race? A pink milk carton, sweatband or (for real) a gun?

The answer is science.

After decades of pink fundraising, 40,000 people per year in the U.S. alone still die of metastatic breast cancer. Worldwide the death toll is more than half a million per year. Estimates range from 20 to 36 percent of early-stage breast cancers metastasizing. We have only a rough estimate of the num-

ber of people at any given time in the U.S. living with metastatic breast cancer. Right now it's 155,000.

In 2014, MBCA (the Metastatic Breast Cancer Alliance) concluded through its research that a mere 2 to 5 percent of all funding raised for breast cancer research addresses anything about MBC. What? Metastatic disease is what kills people.

Much of the research focuses on preventing metastatic recurrence. That's great, but what about those estimated 155,000, and the enormously high number that must mean for the rest of the world? Sure, we can try to prevent breast cancer by living healthy and so on, but the simple fact is that there is no scientifically known preventative strategy.

In addition, there is no way to prevent metastasis when we do not give the scientific community the dollars even to figure out what causes metastasis to occur.

Still a public health crisis

Yes, you've heard this from me before. Yes, with luck (mine), you'll hear it again. I guess I believe the dire and fatal breast cancer situation needs to change, quickly, using every resource that can be mustered. This does not mean wearing a pink sweatband while you work out, or eating chicken from a pink bucket of KFC. I'm one of the hundreds of thousands swimming the backstroke toward a waterfall while, according to Karuna Jaggar (executive director of Breast Cancer Action, whose mission is "to achieve health justice for all at risk of and living with breast cancer"), breast cancer remains a public health crisis and a social justice issue.

Please be certain the dollars you give are not for stuff that will end up at a landfill or the Goodwill but for research. Some excellent organizations are Metavivor, the Metastatic Breast Cancer Network and Breast Cancer Action. Check out all organizations on Charity Navigator. You might be surprised by what you learn about behemoths like Susan G. Komen for the Cure, and just how much — or, rather, how little — of their massive fundraising is actually dedicated to finding a cure.

This year I've outlived the median survival time of about three years for metastatic breast cancer. I'm one of the lucky ones.

Please remember this October what Karuna Jaggar of Breast Cancer Action said while pointing out that the NFL gives no proceeds from pink products to research: "You can't shop your way out of the breast cancer epidemic."

'YOU CAN'T SHOP YOUR WAY OUT OF THE BREAST CANCER EPIDEMIC.'

Karuna Jaggar | Breast Cancer Action executive director, pointing out that the NFL gives no proceeds from pink products to research

