

Another October and I'm alive!

Disclaimer: I describe my own experience and don't profess to know what others in my boat experience. However, my support group experience tells me that many, many of us are not pink-tutu-wearing, happy-go-lucky survivors. Even so, I can only write of my own path.

By **LAURA SNYDER**
For *The Daily Astorian*

I. Imagine

Even if you survive it (60-70 percent of people do), you may be disfigured — permanently altered by treatment, a body that's yours but not really familiar any more. You may suffer chronic pain from past surgeries and radiation. You may have been thrown abruptly into menopause (chemotherapy does this, as does ovarian suppression, a treatment for hormone positive breast cancer)



if you weren't there yet. You might find your brain, which used to seem pretty on the ball, is sluggish now. Maybe it's harder now to concentrate on reading or conversation.

Maybe your memory is much more compromised than the normal middle aged lapses. You might be one of the unlucky few that lost her hair from treatment and never got it back. Your energy level seems about equal to someone decades older, and a crushing fatigue has become the norm.

Imagine being in your 20s or 30s and losing the option of having children, if that was something you wanted. Or that you're a mother (or father) of young children living in fear of being dead before you can volunteer in their elementary classrooms. Imagine having assumed you would meet your grown children's future spouses and their children, and now wonder.

Your life now has an unwelcome and heightened anxiety that never goes away. Every ache or pain, mild or extreme, could be it, returned despite all the "right" things that you and your caregivers and doctors did and do for you.

All of the above? Welcome to the aftermath of early stage breast cancer treatment.

Enter ... Stage right (er, I mean Stage IV): metastatic recurrence. You take your medicines, you exercise and eat right, you try to re-enter the workforce and put cancer behind you. And yet, there it is one night — a lump in the side of your neck.

II. Reality of Breast Cancer

I'm still alive, but I'm not a survivor. I call myself a cancer patient.

I have metastatic breast cancer, also called Stage IV breast cancer. This means the cancer has spread outside the breasts to other organs in my body. For me these have included liver, lungs, lymphatic system, and brain.

I am on my third line of treatment in a little over two years of living with metastatic cancer. I've had whole brain radiation and two sessions of gamma knife radiation to my brain, during which I wore a metal cage on my head screwed into my skull in four places (here's a self-portrait I drew).

This is a part of breast cancer that is neither pretty nor pink, and certainly not "easy."

I'm one of the lucky ones right now. My current treatment has worked wonders with the biology of my particular cancer and I'm happy to report that I'm currently N.E.D. This means No Evidence of Disease! I get a break from the radiation oncology clinic and the anxiety of finding another treatment. I'll take it, and live my life for as long as it lasts.

The median survival time with this disease is two to three years. Sometimes I wonder how it's possible to live with this knowledge and do things that suggest a future — trip planning, exercising, educating myself, even flossing my teeth for Pete's sake! But we do, we go on.

Let's dispel just one of the many myths October has wrought. The truth is, **breast can-**



Laura Snyder/Submitted Drawing

A self-portrait illustrating gamma knife radiation.

cer is not an "easy" cancer. That's an oxymoron that deserves to leave the lexicon entirely; cancer is never easy, not on the body and not on the mind.

The unique thing about breast cancer though, is October. Many cancers have awareness months, but most disseminate serious information.

Somehow, Breast Cancer Awareness Month has turned into a marketing juggernaut. Somehow, many people think it's cute, or funny.

Somehow, people buy T-shirts saying things like "Save the Ta-Tas," "Check Your Boobies," "Fight Like a Girl."

Let's unpack these. Breasts are not "ta-tas." And when someone gets breast cancer the priority is saving a life, not saving the "ta-tas." It's OK to call breasts "boobies" when you're 4 or 5, but to save lives? Really? To raise awareness of a deadly disease? (Bear in mind that everyone is already aware.)

Even if we check ourselves responsibly like we're told through these "awareness" campaigns, and find the cancer early, 28 percent of us will have our cancer metastasize.

And "girl," really? Don't patronize us. We're supposed to think we can "fight" or "battle" this disease into remission, but our responses to treatment are dependent on the biology of our particular individual cancers, not on how hard one "fights."

These slogans, just three among hundreds I've seen, and events like No Bra Day add to the scum of product sales and cheerleading that infantilize and sexualize this horrid disease without doing anything to help the supposed cause — to end breast cancer.

Meanwhile, those of us who are metastatic patients (which is incurable), suffering it for the remainder of our lives, are left wondering where all this money goes and what our lives are really worth.

Research progresses, very slowly. But the vast majority of that new research does not address metastatic TREATMENT.

There are an estimated 150,000 people (this is the low end of the estimate) in the U.S. alone actually LIVING with metastatic breast cancer, and more than 40,000 people a year die of the disease.

I participated in an advocacy training in April 2015. Seven of the 31 participants have died since. That's 23 percent of our group in a year and a half. It's soul crushing to think about.

The 40,000 statistic has not changed significantly in the last four decades, despite of all of the money raised by organizations like Susan G. Komen "for the cure."

I'm all for research on prevention of metastases — the new research buzzwords (I would love for others not to suffer this in the future), but what of the six-figure number in whom metastases already live?

III. Yoga is Good!

I am a regular yoga practitioner. The benefits to my day-to-day life have been astounding.

One of my advocacy projects was and is working with Columbia Memorial Hospital and my yoga teacher to offer adaptive yoga for cancer patients.

I'm happy to say we are in our third series, this one 15 weekly sessions. We haven't charged money for it and we've expanded the opportunity to include any cancer patient in any phase of treatment, as well as pulmonary rehab patients.

Very gentle yoga is proven to improve breathing and reduce stress, anxiety, and depression. It also strengthens the body without impact on muscles and joints. These benefits can both make treatment easier to tolerate and make living every day a happier experience.

If you have cancer or chronic pulmonary issues you can call Cindy Nemlow at Columbia Memorial Hospital (503-325-4321) to register.

IV. Action (of course!)

Many people want to contribute to help the fight against breast cancer. Money raised for awareness campaigns is not productive any more. The world is aware.

Money is desperately needed for RESEARCH: to find breast cancer's cause; yes, to prevent metastasis (this is what people actually die of), and **to develop and improve treatment of metastases, for the many people suffering with and dying of metastatic breast cancer.**

Not only must we raise money for organizations doing and promoting this work, we must lobby those organizations who don't seem to or are just beginning to get it, such as the Susan G. Komen Foundation and the National Breast Cancer Coalition.

If enough of us shout, I think they might

Writer's Notebook

CONTACT YOUR LEGISLATORS

OREGON LEGISLATORS

U.S. Sen. Ron Wyden
www.wyden.senate.gov/contact
Twitter: @RonWyden

U.S. Sen. Jeff Merkley
www.merkley.senate.gov/contact
Twitter: @SenJeffMerkley

U.S. Rep. Suzanne Bonamici
www.bonomici.house.gov
Twitter: @RepBonamici

WASHINGTON LEGISLATORS

U.S. Sen. Patty Murray
www.murray.senate.gov/contactme
Twitter: @PattyMurray

U.S. Sen. Maria Cantwell
www.cantwell.senate.gov/contact
Twitter: @MariaCantwell

U.S. Rep Jaime Herrera Beutler
www.herrerabeutler.house.gov
Twitter: @herrerabeutler

HR 1197: ACCELERATING THE END OF BREAST CANCER ACT

Sample letter, tweet, or phone call:
"Please amend HR 1197 to include metastatic TREATMENT research. 150,000 or more are already living with mets and need better treatments for quality and duration of life!"

Contact both your own legislators and the bill's sponsor: U.S. Rep. Kathy Castor, D-Miami

Website: www.castor.house.gov/contact
Twitter: @USRepKCastor

listen, and some already are. National Breast Cancer Coalition helped put together a bill that's still in subcommittee in both the House and the Senate that does not address dollars for metastatic treatment improvement and development.

You can contact your legislators and the bill's sponsor (see box) to ask them to amend the bill — H.R. 1197 — to include metastatic treatment.

Vice President Joe Biden has begun an enormous, sweeping, and necessary initiative called the Cancer Moonshot and I believe he will continue this work long after he is no longer the vice president. Ask the Moonshot to include improving metastatic treatment into its goals (see box for contact information).

And finally, MET UP (think ACT UP for metastatic breast cancer), a direct-action group whose co-founders are members of my advocacy training group, is part of a consortium putting on The Stage IV Stampede in Washington, D.C. on Oct. 13. It will be a day of lobbying and advocating, including a One-Mile March on the Mall and the second annual D.C. Die-In.

Even if you can't go to D.C. you can participate. Metavivor has set up the opportunity to have meetings with your reps scheduled in your own district. Register at www.action.metavivor.org.

I'll finally end with this. As Metavivor's website states, "You do not need to be an expert to help create positive change. You just need to stand up and speak out!"

Laura Snyder is a wife and a mom of two newly minted adults. A former Astoria School Board member and independent bookseller, for the last four years she identifies as a professional cancer patient.

Some sympathy for the Republican presidential candidate

By **FRANK BRUNI**

New York Times News Service

Go ahead and laugh at Donald Trump's claims that he was foiled by a finicky microphone on Monday night, but I can relate. When I write a bad column, it's all my keyboard's fault.

The other columnists have reliable keyboards. I'm not saying it's a conspiracy, but they do. Reach your own conclusions.

When one of them taps out a beautiful sentence, a beautiful sentence appears on the computer screen, just the way it's supposed to.

When I try to tap out an even more beautiful sentence — and my sentences are amazing sentences; you can't believe these sentences — I have to press and bang and hunch closer to the desk and bang even harder and still you never know.

The sentence winds up mangled. It lacks a verb. Or it sprouts an adverb ("bigly," anyone?) that sounds ridiculous, though I'm not. Readers experience a rant where, really, there was eloquent reflection — or would have been, if not for my keyboard. A "sniffle" sneaks into the equation when there wasn't any "sniffle" at all. It's just a nasty trick of that keyboard. A defective keyboard, which the other columnists don't have.

And the extra effort that this keyboard demands means that I'm dehydrated and have to drink more water than they do. It's not that I have flop sweat. I'm no Marco Rubio, for crying out loud. It's not that I lack stamina. I'm no Hillary Clinton.

No preparation

You've read this far and you're thinking: Dear God, he didn't prepare for this column. Not a whit. We were warned that he might not, but we dismissed that as expectations-lowering spin, because surely he appreciated

the magnitude of the moment, the consequence of his task, an analysis of the first-ever general-election debate between a woman and a circus act. But instead of boning up on the issues, reviewing past debates and crafting a few can't-miss zingers, he just pumped air into his hair and more air into his head and sauntered into action as if the sheer, inimitable wonder of his presence would be enough.

To which I say: President Barack Obama plays too much golf. And Rosie O'Donnell has been vicious to me. Very vicious.

I like to test my audience's math skills. Only one of the following four sentences is arithmetically plausible; you tell me which. Clinton has been fighting ISIS her entire adult life. If she hadn't been involved in the Vietnam War, it would have ended sooner and better. By leading from behind, she enabled Adolf Hitler's rise. My federal tax rate over the last five years is a negative integer.

I also like to show restraint. There

are all sorts of things I could bring up in this column that I'm not going to. I could talk about the candidates' marital histories. I could summon sexual scandal. But, see, I'm not doing that, because that's beneath me, though I reserve the right to do it in my next debate column, because it might not be beneath me then.

Just skip it

If there is a next debate column. We'll see. Rudy Giuliani says I should skip it, because I'm not being treated fairly, and if this journalism thing is rigged against me, I can't just sniffle and bear it, can I?

I have a club in Palm Beach, investments in Charlotte, property in Chicago. That's not relevant to the previous sentiment, but I don't stack my points in some coherent, logical order. That's what overly programmed, endlessly rehearsed columnists do. Besides which, I like to brag.

I've been endorsed by organi-

zations that have never endorsed a columnist before. A few may not even exist. But they see in me something that they haven't seen in my peers. Just ask Giuliani, though you'll have to wait your turn. He has live appearances on three different networks over the next two hours, including a medical panel, moderated by Sean Hannity, on the question: "Clinton: Fully Recovered or Drugged Out the Wazoo?"

I don't need drugs, because I have a great temperament. Great humility, too, but I'd put my temperament above even that. I don't complain when people gang up on me, and they're constantly ganging up on me: It's disgusting how they behave.

Whatever. I wrote a great column anyway. I'm thrilled with this column. All of the polls show that it's a huge success. Wait, what ... they don't? You must be looking at the wrong polls. Or the pollsters aren't honest. So many dishonest people out there. Not that I'm complaining.



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