

April 24, 2023

To Chairman Lipps and members of the House Public Health Policy Committee:

I am writing to you today in support of House Bill 28, designating March as Triple Negative Breast Cancer Awareness Month. I am particularly passionate about this cause, as I myself am a four-year survivor of Triple Negative Breast Cancer (TNBC).

I had been working in Alaska for nearly eight years as a National Marine Fisheries Service observer and was in the middle of the Bering Sea, when I found a lump in my breast. At work I gathered data on commercial fishing vessels, helping to ensure the fisheries remained sustainable. I absolutely loved my job and lifestyle. I could spend a couple of months each year at home in Ohio, several months in Alaska, and fit in some extended travel in between. When I first found the lump in July 2018, I felt certain it was simply a cyst that would eventually disappear on its own. Fast forward to the end of September 2018, and I was back home in Ohio. Four days after laying my maternal aunt to rest from pancreatic cancer, a scheduled mammogram and ultrasound revealed the lump that I thought was a cyst presented as a clear indication of breast cancer. I was 32 years old.

The biopsy results came back on October 5, 2018, and I was officially diagnosed with TNBC. During this follow-up appointment, my mother and I were informed that TNBC is a particularly aggressive form of breast cancer. Imaging showed I had six tumors in my left breast, totaling 12.9 cm, or about five inches, as well as cancer cells in the lymph nodes. My aggressive cancer would be treated with an equally aggressive, seven-month treatment plan, consisting of a single mastectomy with lymphadenectomy, eight rounds of dose-dense chemotherapy, and 25 rounds of radiation. Like most TNBC patients, I would endure the “slash, poison, and burn” method of cancer treatment.

Since TNBC cancer cells lack the hormone receptors found in other breast cells (both in healthy cells and in cells found in other forms of breast cancer), there are no targeted chemotherapy options for TNBC. Instead, oncologists commonly use Adriamycin, nicknamed “The Red Devil.” Unable to specifically target cancer cells, this powerful chemo drug wreaks havoc on the body, killing any fast-multiplying cells, leaving hair loss, mouth sores, horrible nausea, heart damage, and other side effects in its wake.

When I was first diagnosed, I thought my diagnosis would simply be a speed bump in life. I would take a year off for treatment, grateful to be living with my parents for their support during the challenge of treatment, then surely I’d be back in Alaska like before, just with shorter hair. I was absolutely devastated a few weeks later, when I realized this disease was not only a very real threat to my health and my life, but my beloved career and traveling lifestyle would also be taken from me.

It was more than a year and a half before I could return to work. During that time, I started a blog called Adventure After Cancer, where I provided tips and resources for getting through all the stages of breast cancer treatment. I also wrote about my travels, both in Ohio and abroad, to convince others (and honestly, myself) that the best years of my life were not behind me, and that there is still beauty, joy, and

adventure to be had, even after the trauma of cancer. I have met hundreds of breast cancer survivors through Instagram, and I have had the privilege of taking road trips in order to meet some of these incredible women in person.

Quite frankly, I am one of the lucky ones. The slash, poison, and burn treatment regimen has worked, at least so far, in preventing a recurrence. This coming October will mark five years of survivorship – a huge milestone in the TNBC community, as our risk of recurrence drops to equal that of other breast cancers at the five-year mark. For the first two years after diagnosis, TNBC has a rate of recurrence of about 50%, versus an average of 33% for other types of breast cancer. Though I still endure some side effects of treatment, I have been able to return to working at sea as a biologist, and am writing this letter to you while aboard a ship in the Gulf of Mexico.

Many women have not been so fortunate. There are Instagram accounts I still follow, knowing full well that a fellow survivor will never create another post, yet it feels disrespectful to unfollow her account. Some of the women I made a special trip to see, having the joy of meeting them in person, hugging them and laughing with them, but they are no longer around for me to plan a second visit. Several of these women were diagnosed in 2018, as I was. Several other women, diagnosed with TNBC a couple of years after me, are enduring the pain, fear, and complications that come with Stage IV progression. And a few of these women, with whom I connect almost daily, are running out of treatment options.

As I mentioned previously, TNBC has no targeted therapy, because scientists are not sure what these cells feed on or what spurs their reproduction. Without the knowledge of how to interrupt the cell reproduction cycle, TNBC patients are left with few effective treatment options. TNBC is the rarest form of breast cancer, consisting of only about 15% of diagnoses. Understandably, the majority of funding and progress toward breast cancer treatment has gone toward the types of breast cancer that are more easily targeted and that make up a far greater portion of breast cancer diagnoses. However, those of us with TNBC, the most aggressive form of breast cancer, are left with the fewest number of treatment options. As the cancer continues to grow and treatment options dwindle, those with TNBC are left hoping for a clinical trial that is willing to accept them. TNBC is most common among young women, especially those with a genetic mutation such as BRCA. Thus, the majority of these TNBC patients, enduring a Stage IV diagnosis and limited options, are only in their twenties and thirties, and many of them wonder if their young children will even remember their mother.

Every October our nation has Breast Cancer Awareness Month. Despite all of this awareness, the average person has no idea that there are multiple types of breast cancer. They are even less aware of TNBC, how aggressive it is, and the limited number of treatment options available. In fact, with October's parades of pink tutus and smiling survivors, many of my friends and acquaintances have been surprised to learn that breast cancer can still be so deadly.

I believe with House Bill 28, we in Ohio can help bring awareness to this devastating disease. With awareness, young women will realize they are not exempt from cancer, and will learn the importance of self-exams. Awareness also has the potential to spawn more research into treatment options. Adriamycin, commonly used to treat TNBC, is used for a number of other cancers, including leukemia, lymphoma, stomach, ovary, thyroid, lung, and bladder cancers. I believe it is possible that a new

chemotherapy option powerful enough to destroy TNBC will also prove useful in treating other aggressive cancers. I sincerely hope for more self-awareness regarding women's health, and the initiative for additional research to soon follow. But we can start today by simply bringing awareness to our fellow Ohioans that TNBC deserves our attention, and dedicating each March as Triple Negative Awareness Month through House Bill 28.

Thank you for your time and for allowing me to share my story. I believe awareness of TNBC through House Bill 28 is worth your support.