



WARRIOR CAPS

BECAUSE SOME WARRIORS HAVE HAIR

My Journey with Breast Cancer

I discovered a lump on my own on June 20, 2018. My self exam was prompted after many phone calls with my sister in law, whose older sister had been diagnosed with Infiltrating Ductal Carcinoma on June 16th. Her frightening discovery made me think that it had been a few months since my own self exam, where I found my lump.

The next morning I was in the OBGYN office by 11:30am, where they confirmed that I would need to have the lump investigated by the breast center. I was able to be seen by the radiologist at Gavers Breast Center the next day, where my mammogram detected “dense” breast tissue. The radiology nurse decided to investigate further with an ultrasound, where she discovered 3 suspicious lumps in my left breast.

I had to wait an entire week before my biopsy on June 28th. During this time, I visited my parents to fill them in. My mother admitted that she had also discovered a lump, and she had a biopsy scheduled for June 29th!

My biopsy was locally numbed, and the radiologist took 5 core samples per lump. It was a very uncomfortable and unnerving procedure!

On the morning of July 2nd, I received the phone call from Dr. Perlis, it was confirmed Stage 1 Infiltrating Ductal Carcinoma, which was both hormone receptor and HER2 +. I was devastated. How could I be facing breast cancer at 37 years old, with two sweet little boys to raise and a bright future ahead of our family? Unfortunately, my mother received the same phone call that day – we were both diagnosed with breast cancer.

I spent the following 2 weeks in an out of oncologist offices, my OBGYN office, the breast center and the hospital undergoing multiple tests. Thankfully, the MRI showed no cancer in my lymph nodes, and that the tumors were contained to the bottom left quadrant of my left breast. My genetic testing also came back clean.

My initial surgical oncologist meeting was with Dr Gia Compangoni, who I felt an immediate connection with, through Advocate Good Shepard. She then set me up with North Shore Oncology, with Dr Thomas Weyburn as my medical oncologist. He had to deliver the hardest news, which was my treatment plan. 6 rounds of TCH+P chemotherapy every 21 days.

I spent a lot of time struggling with the thought of losing my hair, when my research found “cold cap” therapy. Friday, August 3rd was my first chemotherapy treatment. I had to take a steroid the day before treatment, which really didn’t bother me that much. We arrived at 8:30 in the morning and I had my blood drawn, then met with the nurse practitioner Laura to review my plan. The oncologist nurse, Lisa, was wonderful and explained every step we would take. They started with another steroid and an anti-nausea medication. Then the Herceptin and Perjeta (the specific chemo to kill the HER2) and then the hard stuff. I drank as much water as I could possibly stomach during the infusion, to try to flush out the chemo as quickly as it was going in. David perfected the capping process, and changed them every 30 minutes to keep my hair follicles frozen during my infusion. It was awfully painful, and freezing cold, but I would try anything to save my hair.

I felt ok during the infusion, I got up to use the restroom a lot and ate a small sandwich, crackers and peanut butter and watermelon while I was there. I went to bed that night right after the boys, around 7:45pm.

When I woke up Saturday morning, I felt like I had the worst hangover of my life. I was lightheaded, nauseous, bloated, weak and just feeling terrible. After I passed the 24 hour mark and took 2 anti-nausea pills, I thought, “ok, I can do this”. I basically laid in bed most of the day, getting up for small trips downstairs and more water, and then I went right back up to bed. Sunday morning and throughout the day were much of the same. I kept telling myself “this is manageable” with the medication and rest. But Monday was the same. And Tuesday was the same. And Wednesday was the same. And Thursday was the same. Friday was my follow up appointment at the medical Oncologist office. I got on the scale and it read 108.9 lbs and I completely lost my mind. How could I lose that much weight in one week? I was beside myself, crying and feeling completely hopeless. The nurse practitioner, Laura, came in the room and was a bit taken back by my condition. I told her about the horrible diarrhea, how bad I felt, how tired I was and how I could not believe that I couldn’t figure out how to manage what I was going through. She told me I had waited too late to get it to see them, she thought I was probably dehydrated and needed fluids. After I got my blood draw, the nurse set me up with 1 liter of fluid through my IV. I felt a TON better after I got that pumped into me.

That weekend was much better. We spent a lot of time as a family, went out to breakfast on the boat, and just enjoyed our time together. I was still really tired, I went to bed by 8:00pm every night, but I was feeling much better. I drank 3 liters of Pedialyte over the weekend to bring my electrolytes back up, which was also helpful.

The following week was pretty normal, I still had the diarrhea but I finally figured out how to manage it with the prescription medication, and by Wednesday the 15th it was finally gone. I got to go to Madison for designer training the week before my second round of chemo. It was a great week with the designers, and a really nice break from the reality that I was facing at the end of the week. By Thursday night, the anxiety of round 2 was

starting to get to me. But I woke up Friday morning just ready to face it, got to the office extremely early to claim the back corner spot for privacy, and started the whole process over again. My weight was right back up to 117 lbs, so that was a bit of a relief. I felt the same as I did the first time I got the chemo in the office, just nothing really. I had soup for lunch and David got a burger from Culvers. We used the cold caps and I worked most of the time that I sat there. I was shocked at how many people reached out that morning with well wishes for my second round.

Ken and Linda arrived that afternoon for Connor's birthday celebration weekend. Saturday was Connor's 4th birthday, so Mom and Dad, Ken and Linda, Sharon, Tom, Brittany and her boyfriend and Lori and the kids came over for a BBQ to celebrate. Even though I tried to delegate as much as possible, I ended up over-doing it that weekend. It was a very hot weekend, the kids just wanted to be outside, and Linda was not helpful because she could not stand the heat herself. So I sat outside with the boys and did what I could to entertain them, while Ken and Linda sat inside all weekend.

Monday brought the uneasy, queezy feelings back – similar to the first round after day 3. I felt ok on Tuesday and Wednesday (except for the diarehea), but by Thursday I was feeling like I was hitting a wall again. Friday morning I woke up feeling really bad, I went to lunch with a designer and then straight to the oncologist office for more fluids. Even after 1-1/2 liters of fluid, I felt bad. I spent the weekend trying to relax, but I was terribly tired and had a constant headache all weekend long.

By the following Tuesday, a large rash popped up on my left side. I went straight to the oncologist office again, and the nurse (Julie) diagnosed it as the beginning stages of shingles. Seriously! She prescribed me a heavy medication (500mg x 3/times a day) and told me to try not to scratch or irritate the rash. After 4 days, it did not change, and the medication was really bothering me, so I stopped taking it. The rash then started on my right side, which gave me the impression that it could not be shingles. Finally, after 11 days of feeling bad, I rebounded and started to feel "normal" again. I was able to eat most foods, have solid stools, and sleep at night. Just in time for Round 3, on September 14th.

Lisa Sleckman from Liam Brex drove all the way from Glen Ellyn to sit with me at chemo that day. My Dad was also there, and helped change my cold caps, kept me wrapped up in blankets to stay warm, and just made sure that I was as comfortable as I could be that day. David was able to get Connor back and forth to pre-school, and took me home at the end of the day. That weekend and following week was much of the same.....feeling like the worst hangover/flu I have ever had with absolutely no relief for 11 days. No appetite, no energy, nothing. Thank God I was halfway through!

I had an appointment with Dr Compagnoni the following week, and she looked at the tumors with an ultrasound. The smallest tumor had disappeared. The second tumor had shrunk by ½ its size. The largest tumor, which is the one I could feel, was still hanging on tight, had hardly changed in size at all and was still prominently able to be

felt. Still, Dr Compagnoni was happy with what she found and felt that we were on the right track with my treatment.

Round 4 was October 5th. My Dad and Steve Weiner were there for that appointment. Steve was fascinated by the cold cap process – as most people are when they see it. I never really gave it much thought, I just knew that I did not want to lose my hair and this was how I was going to keep it. But when you sit back and think about it, it is a real miracle that my hair was saved from chemotherapy just from freezing the hair follicles in my head. It is fascinating! I got smart after this round of chemo and made an appointment to come in and get fluids the following week. 6 days after treatment I broke out with a horrible rash on my face. I looked like an adolescent teenager going through puberty. I felt terrible, was unbelievably tired and it took 12 days for me to rebound after Round 4.

Round 5 – on my birthday! Lori came with me for chemo this day. She helped my Dad change out the cold caps, got my soup, and watched in horror as that poison was pumped into my body. Much of the same this weekend – feeling just horrible, not being able to eat, and completely wiped out. I made another appointment the following Monday for fluids. I broke out again with a rash on my face. I started smoking the buds which did help my appetite when I had the energy to eat. And I tried Miracle Fruit – little berries which help your tastebuds with flavor again so food was a little appetizing.

We dressed the boys as pirates for Halloween and I went to Connor's pre-school party. It was cute to see all the kids in costume and how excited they all were. That night, we took the boys trick or treating and I just pushed through. I felt horrible, but I could not take the fun of Halloween away from the boys and I did not want to miss the experience with them. It was the first time they really got excited about knocking on someone's door and saying "trick or treat!" They absolutely loved it. Unfortunately it took all of my energy and the rest of that week was brutal. It took 2 full weeks for me to recover from this round.

Finally, Round 6, on Laura Paulette's birthday, November 16th. I woke up that morning just ready to face it. At the same time, absolutely dreading it. I started to feel sick in the morning before I even went in just from body memory. It made me completely crazy. I would lose my mind over little fights and slam my hands on the counter, scream at David and cry uncontrollably. Our arguments took EVERYTHING out of me. I contemplated killing myself just to end the sickness and the pain. But then God kept me going. God held me, and the prayers from our family and friends were so powerful. I could feel the energy and it helped me through it. It was incredible, almost miraculous.

The following Monday I was back at the oncologist for fluids. I got 2 liters and felt just slightly better. I worked from home most of that week. The next week was our big National Sales meeting in Madison, so I did everything I could to save my energy for that trip. Then, at the end of that week, I was headed in for the mastectomy on December 7th. I visited Dr Compagnoni again to check the status of the tumors, and

she said that two of them had disappeared, and the final one had shrunk to ¼ of its original size via ultrasound. I also visited Dr Madry, to discuss final details before the mastectomy.

I went in for fluids and to check my weight one more time before driving to Madison that Monday. I got 2 liters and I was down to 107. Dr Weyburn told me that if I did not put on at least 5 pounds that week, to put me above 110, they could not do surgery. I though Madison would be the best place to be considering the food!

The surgery took 9 hours. Dr Compagnoni removed the remains of the tumors and all of the tissue in my breasts, and Dr Madry put in the expanders, filled them with 100 cc's of saline and stitched me up. David said I woke up screaming in pain, which I do not remember at all. I do remember waking up and pulling at the oxygen tubes that they had shoved in my nose and throat. When I woke up again, they had moved me to a regular room on the second floor. I was hooked up to an IV that was administering liquids and pain meds as needed. I called for the pain medication every 4 hours. The drains they had installed simply hung out of two holes in my side. I do not remember much more of the first night.

The second day they had me up and walking around the hallway. The drains pulled on my sides and were terribly uncomfortable, but I did not have a choice but to deal with them. David gave me a sponge bath to get me cleaned up a little bit. I could not lift my arms or put weight on them to get in and out of the bed hardly at all. It was so terribly painful. When they say that you can't even put a shirt on by yourself they are not kidding. Any bit of weight on my arms and/or chest was excruciating. Because I was in so much pain, food tasted horrible to me. I was able to eat a little bit of breakfast and then small snacks that day until dinner. I had to move so slow. So unbelievably slow. My heart just breaks for those who are in that kind of pain, every day, with no relief. How do they manage?

I asked the nurses if I could stay another night just to give my body one more evening of rest before going home. I was afraid that the boys would be overwhelming for me, so the safest place to stay was the hospital. I learned how to manage the drains, took a shower, and move around the hallways a little better. The drains still bothered me a lot, but again I had no choice but to deal with the pain of the holes in my sides. Sharon and Brittany came to visit me that night. I started feeling better, with more of an appetite, so Lori brought me Domino's pizza for dinner. It was amazing.

The next day was Sunday, and I was released to go home. David brought my car so it was easy for me to get in and out, but I could not even open the car door without horrible pain in my chest. During the drive home I was dizzy and I did not feel very well. I was anxious about going home to the boys, our new aupair, my in-laws and not having the care from the nurses. We got home and I spent a little time downstairs with the boys, and then I headed upstairs to rest.

The weeks went by and the pain got better. I had those awful drains in for 11 days. What a relief to have them removed! I started the fill process just before Christmas. The expanders were filled every week until I reached 500 cc's. I had my exchange surgery on April 16th, for just enough recovery time to be able to water ski by Memorial Day weekend.

As I started to regain my strength and my motivation, I decided that life is just too damn short and we are going to L-I-V-E!!! We put the boat in as soon as we could and spent as much time on the water as possible all summer long. Unfortunately I starting gaining weight at a regular pace, about 2 pounds every 3 weeks, due to the medication and early menopause. So, I was not exactly parading around in a bikini, but I enjoyed summer with my family regardless.

As July 2, 2019 arrived I sat back to reflect on the year that went by. A whole year of my life, basically stolen from me. Between the sickness, the memory loss, and the pain my body went through, I will NEVER be the same. I still can not believe I actually experienced and beat cancer. It is horrifying. But I am so thankful to God for my strength, to my family for their support, and to my friends for their prayers. Every day is a gift, and I am thankful. I pray that each cancer survivor that I meet feels the same.