mesh. undies.

December 31, 2016 By Lindsay Norris

Yep, mesh undies. You know, the ones you get from the hospital when you have a baby?! Well — they are once again here to save the day! More on that and other new updates further below.

I haven't posted in a while… at first I think I was probably a little overwhelmed at the attention my last letter got. Wow, such an amazing experience to have my words shared by several media and news outlets. My letter has had almost a million views in hundreds of countries. It's been translated to three other languages that I know of and I've heard of some hospitals using it in their curriculums. Some other exciting things are possibly in the works as well (no, Ellen hasn't called haha). I certainly wasn't expecting so many people to read it, but my favorite part of this whole experience has been the outpouring of emails and messages I've received from cancer patients, survivors, caregivers, healthcare workers, etc. Having people tell me that I "nailed it" or I validated their feelings or that I was able to put into words what they've been trying to explain just warms my heart. I still have emails coming in each day and am wayyy behind on replying! I can't believe some of the elaborate, heart-felt, long, long messages I've gotten — I want to write each person an entire book back. I've always known there is so much love and support in the oncology community but wow! I really am humbled. I've started just keeping them in an email folder to get back to when I have time or maybe during surgery recovery or future chemo days. I feel so lucky to have connected with so many beautiful people and the nurse in me feels proud I've been able to make a positive impact. It's been very therapeutic for me as well — I've had many people send survivor stories full of hope and encouragement! It all came at just the right time.

A little recap — I started chemo (oral pills) and radiation at the end of October. This is the standard first phase of treatment for my stage/ type of colorectal cancer. If I were to briefly describe each week since starting chemoradiation it would look something like this:

Week 1 — hmm… anticlimactic.

Week 2 — oh, this schedule isn't that bad — I can keep it up. I feel a little nauseous but ehh, meds cover it. Wait, grrr… my tumor marker labs went up (CEA 18… it was 12 at diagnosis), what does this mean — is my cancer getting worse. sigh — wait and see…

Week 3 — This really isn't bad, what do people really complain about anyway.

Week 4 — ok, who THE HECK hit me with a truck! I literally cannot keep my eyes open and I can't even look at food. Frustrated I'm losing too much weight — bring on the Ensure shakes!

**check up in here: Saw the NP to review labs and symptoms. Thankfully my tumor marker levels had gone back down a little (10) so that shows some response but it was hard to not be skeptical. I had her check my skin and also was concerned because I saw and felt a few lymph nodes in my groin. I asked if she'd check them out… "um, Lindsay"… "yeah"… "those are veins"… "OH yeah yeah, I knew that!" (Quietly sneaks out to go find old anatomy textbook.)

Week 5 — Wth, when did I sit on a hot iron? owwwwwie

Week 6 — nope, just nope. I'm over this. but yay I'm finished going every day!

Week 7 — Ok ok, jokes on me… I had my last treatment a week ago and my rear still hurts. What gives? I can't even wear real underwear! (enter: mesh undies)

Week 8 — Phew, starting to feel a little better. Skin is healing and starting to peel. eeek. Hey look, I gained a pound! (remind me to buy stock in Ensure)

Week 9 — Alllmost normal, maybe just a little achy. Do I have to give up the mesh undies though?

Week 10 — Yep, I officially feel great! 100% normal! Just in time for the holidays — what a perfect distraction

That brings us to this week. If I'm honest, it was a roller coaster. While I was doing radiation I focused on keeping up with the schedule and managing side effects (oh yeah — remind me, also buy stock in Aquaphor) but as soon as it was over, my mind turned to "what's next?" Well, next were some tests to see if any of this is working so far! On Tuesday after the holiday weekend — I got my labs drawn and had a wonderful surprise. All my blood counts were returning to normal and I was shocked to see that included my CEA! CEA (which I've mentioned a few times above) is an antigen found in GI cells that acts as a tumor marker for colorectal cancer. A normal level is below 3, mine has been as high as 18… and on Tuesday it was 2.5! That's it! Normal range. Even for someone without cancer. This is very exciting to have a normal level before the tumor is even removed! I was on a huge high going into my scans on Wednesday morning. I had a CT of the chest, abdomen, and pelvis, and a MRI of the pelvis. Procedures went fine, contrast still tastes gross, and the music still came through in the MRI (I requested Beatles again — this time the first song was "Yesterday"… it even played twice when I was in there for the 45 minutes or so). I saw the report later that day — first thing I noticed was the cancer had still not spread anywhere in my body, thank goodness — that was the most important thing! But then I saw the measurements and was a little bummed. My tumor started at 5 cm and now was measuring 4.3cm. hmm that didn't seem very exciting. But hey it was smaller! I think it's just jarring to still see any measurements at all. Some secret part of me hoped the report would say something like "oh, we can't find any tumor at all". 4.3 still seemed pretty big to me — but talking it through with the nurse practitioner, I was reminded that some of that area that is measured could be just "dead" or inactive scar tissue — and my CEA was still normal so something is improving. AND it IS smaller! ugh it's just so much to take in. Don't get me wrong — I was so thankful my tumor showed signs of response and it hadn't spread, but you just always hope for more. You always want best case scenario. I've found that anytime I get any new information, even if it's "good" — it still takes a while to even

process it. It's too overwhelming to add it to the bank of information you've already wrapped your mind around… how does this fit in? what does it mean? I feel like every result, every decimal point, every twinge or ache, all has such an impact on my future and my chances of surviving. Anyways, like I've admitted — and I have have no clear explanation for the feeling — I was bummed. As I was driving home I kept thinking, "Gosh, I was on such a high yesterday. Yesterday when I saw my low CEA level I was so encouraged and happy. Today, I just don't feel as confident as I did yesterday. Yesterday. YESTERDAY… wait — that's the song from the MRI! The song literally says "believe in yesterday". I smirked, thanked God for another amazing song message — and learned my lesson. Focus on the good, believe in it! and I do!

Today I met with the Oncologist. He sat down with me and shared that he reviewed everything and feels like I've responded even better than what's expected at this point! Wait, what?! He used words like "spectacular", "incredible", "responding beautifully"…ahh no stop, say more.

I'm thrilled… I learned to take a breath and not jump to conclusions. He still believes I could have a great response, we don't know how much is really there or how much is scar tissue until after surgery… and the low CEA is a great indicator that my tumor is really struggling in there (insert evil laugh). So today was amazing (I also got to watch a sweet new friend ring her chemo bell — hi, Amy!), I'm right on track and looking forward to our family vacation next week! My job right now is to relax and gain weight. Thanks, Christmas cookies! Surgery is scheduled for January 23rd! A robotics case with two attending surgeons. I can expect a 4-5 day hospital stay and a 6 week recovery. Pray for the surgery team and for a uneventful recovery period sponsored by Netflix and books.

Overall, I've really been doing well — I've missed very few days of work and have enjoyed the army of a support system I have. I've been thinking about my baby girl a lot. Clearly, the goal when dealing with any type of cancer is to find it as early as possible. I wasn't that lucky — mine has likely been there a while and is quite locally advanced. I keep thinking about what if I had found it earlier… would I have had to do all the same grueling treatments, would I have a better outcome in the long run? I do know one thing… if this cancer had been found earlier… say a few years ago… we would have of course had the fertility discussion with my team. I could almost promise you, considering the traumatic pregnancy and birth I had with my son three years ago, that we would have decided to not delay treatment to preserve any fertility options. We would've decided that it's not worth preserving the chance for a pregnancy that was already so high risk and a tough decision regardless of any cancer diagnosis. And maybe in that scenario I would've only needed surgery, or not so many treatments… maybe in that scenario the survival rate percentage given to me would've been higher and maybe in that scenario I live a long life. But guess what — that scenario doesn't have my daughter in it. I know this was found at the time it was supposed to be. I know she was supposed to be my sweet little girl. And if that means I have to have a larger surgery, go through more difficult treatments, or worse, then so be it. What mom wouldn't do that for their child? Sometimes I cringe at the "everything happens for a reason" motto, so many awful things happen that can't be explained — but I do believe this timing is not a mistake. I also really believe that my pregnancy is the reason I found it when I did! If we hadn't decided to try for another pregnancy that gave me those minor postpartum symptoms leading to

my diagnosis. I likely would not have noticed any trouble until much later — leaving my cancer time to grow and spread. Who else can say both their children saved their life? My family is complete and we are exactly where we need to be.

I find that when I force myself to take one day at a time, I do best. Sometimes my mind will wander too far ahead and think about recurrence risk, survival rates, stats… the thoughts get overwhelming. I have a great feeling about this and have every reason to believe I'll beat it, but I know nothing's ever promised. Whatever plot my story takes on, I know it will be a beautiful one. I just really want to be the one here to tell it.

XO, Lindsay

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