

Being a PREvivor - Julie Sanders



I am not a SURvivor – I am a PREvivor, meaning, I never had cancer. I did, however, have genetic testing done when I was 35 due to my family’s extensive history of breast and ovarian cancer. My test came back positive for the BRCA-2 gene, which typically means an increased risk of about 80% after age 50, however (again) due to my family’s extensive history and my mother’s diagnosis at age 37, my risk factor was more like 90% at my current age. I decided since I was only 2 years away from the age my mother was diagnosed (and hers recurred two years later in her bones), I was staring straight down the barrel of a loaded gun. I need to make a move, and fast. I opted for a prophylactic double mastectomy plus reconstruction. My surgeries occurred about 3 months after I got my positive test, and in the interim we actually did find a tumor in my breast (benign – whew!). Later that year, I had a total abdominal hysterectomy and oophorectomy. All of this occurred in 2011.

I’ve since then turned my experience into an advocacy movement and have done several talks at cancer symposiums, at cancer treatment centers, and individual doctor’s offices in which my primary audience was doctors and nurses. I’ve also done a couple talks at work in which my audience was former patients, family members of patients, or people like me who were worried about cancer and wondering if they’d ever get it. When my audience is doctors, my message is typically that if you’re proactive enough, you can make the choice about the kind of life you want to have, and although you may not be able to avoid painful surgeries, you can opt out of having to do chemotherapy through it all. Also not to only think about the despairing patient in your office, but to also think beyond into family members who may not have cancer yet – a genetic test could help multiples of family members, even if it’s too late for the person undergoing treatment at the time.

When my audience is potential patients, I talk about what my experience was like and what the surgeries entailed, and quite a bit about the feelings I went through. I also stress that a positive genetic test does not mean a person has to do all the prophylactic surgeries like I did; it only opens up an array of choices for early detection that weren’t available to them without knowing the genetic risk – such as MRI’s twice a year, and more frequent mammograms. Testing also means that they may find out they don’t need to worry. Imagine if it was me – who had every single female family member on my mother’s side suffer either breast or ovarian cancer – but I got a negative test result. My risk factor would be a smidge worse than the general populous of 1 in 8 (since there would be a familial risk), but it surely wouldn’t be 90%. I also wouldn’t have to worry that the gene was passed on to my children, because they can’t inherit it if I don’t have it. Having the result I did forced me to make a decision that changed my life (GAVE me life, in my opinion), and having the opposite result would have also changed my life – in that I wouldn’t have had to continue living under a shadow of wondering if cancer was going to come and get me, too.

Outside of doing talks, I’ve also done Susan G. Komen 5K’s (all running, no walking for this girl!) and I also did a RAGNAR for Myriad in Utah. Ragnar is a 200-mile relay race over about a 36-hour period (depending on how fast your team is) which benefits Huntsman Hometown Heroes, a cancer research foundation. Myriad puts a team or two together once a year of employees, and always includes a couple of patients to help their employees remember exactly what it is they are working for – puts faces to numbers, affirms the kind of difference they can make, and shows former patients now pushing themselves to the limit. The entire experience was very uplifting and inspirational for all involved.

I am happy to share that my mother, who you may have assumed passed away since the cancer came back in her bones, is STILL ALIVE and all her cancer is GONE! Her story is nothing short of a miracle. She has not made advocacy a passion like I have; she chooses the route of just giving thanks to God for the gift of life, which I greatly admire!