MY BRCA STORY
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"The whole is more than the sum of its parts"
Aristotle

2010 was a very difficult year for me and my family. However, from my experience I learned great lessons of self-worth, beauty, and empowerment. I am greater than the sum of my parts.

Like a tinted moisturizer with SPF, I am luminous, authentic, joyful, and now better protected. Like a soothing eye cream, the crow's feet around my eyes have been diminished knowing that I have drastically reduced my risk for any future "wrinkles" in my life. I have become a more solid foundation for my family, while discovering a newfound purpose to help others.

I am what is called a previvor--someone who has never had cancer but has an extraordinarily high risk for getting it. I inherited the BRCA1 gene mutation #5385 (also known as #5382) from my Dad. It's one of the three founder mutations associated with people of Ashkenazi Jewish descent. I had up to an 87% chance of getting breast cancer in my lifetime and up to a 50% risk of getting ovarian cancer in my lifetime (compared to the 10% and 4% respectively of the normal population). I chose to be fierce and strong. I chose to be fearless and to conquer. I made the decision to be here for my husband, my kids, and most importantly myself. I let go of my dream of having more children and instead took on the side effects of menopause. I said good riddance to my ticking time bomb breast tissue and welcomed my new breasts with implants and minimal scars. I became my own advocate and ultimately a pioneer in my family.

The family tree on my father's side looks like a road map for hereditary female cancers. My grandmother Lillian died in 1934 at age 33 from breast cancer and what I believe was also most likely ovarian cancer as well. Her mother died of breast cancer, plus several of my father's female first cousins had breast cancer. However, we only really looked at our family tree when my sister Jan was diagnosed and treated for both ovarian cancer and uterine cancer (two separate primary cancers) in the fall of 2008. It was then we learned that she carried the BRCA 1 #5385 (aka #5382) genetic mutation. we had heard of BRCA testing but simply weren't aware of what testing actually meant. We didn't realize that there had been two identified gene mutations--BRCA1 and BRCA2. Plus, we didn't know that there were many different specific mutation numbers within the BRCA1 and BRCA 2 mutations.

We had no idea that if you were of Ashkenazi Jewish descent, that alone raises an eyebrow for concern. One out of every 40 Jewish people carries a mutation in the BRCA1 or BRCA2 gene. We had no knowledge that the different mutation numbers meant different things in terms of cancer risk. In addition, we learned that a BRCA gene mutation can be passed onto you from either your mother OR your father and that you have a 50% percent chance of inheriting it from that carrier. More than that, a BRCA gene mutation in a woman has also very different and significantly higher risks associated with it than if a man carries a BRCA gene mutation.

At the same time my sister was undergoing chemotherapy for ovarian cancer, my dear friend Kristin was battling triple negative breast cancer from her own BRCA1 mutation (not an Ashkenazi Jewish mutation). Two BRCA cancer battles were happening right in front of me altering my perspective on everything. I credit both Jan and Kristin with saving my life. Being BRCA positive put me at great risk for getting cancer, plus I had extremely dense breast tissue which is known to "hide" cancer (it's difficult to detect breast cancers through regular mammogram screening if you have dense breasts).

For me, I saw only two choices in front of me--do nothing or do something. I could sit around with my high risk percentages and dense breasts and wait to see if I would get a hereditary female cancer or I could have prophylactic surgeries and virtually cure myself before any issue of cancer would arise. I watched what my sister Jan and my friend Kristin were going through and I thought to myself,

"Yes, I have inherited this very dangerous genetic mutation but I have been given the gift of having options to drastically reduce my cancer risk. Knowing that I can actually do something to prevent what they are going through and even avoid death--I can't just sit on this knowledge and do nothing."

The prophylactic surgeries reduced my risk for breast cancer from about 87% to about 3% and have made it so I will never get or die from ovarian cancer, although I do still carry a small risk (about 1%) for peritoneal cancer (lining of the abdomen). My view is that I simply removed the parts of me that were causing more harm than good. This philosophy was easy for me to take on since I had already been through a major surgery in 1998 to remove a benign brain tumor (an acoustic neuroma) which consequently left me completely deaf in my right ear.

I am invigorated with passion and purpose. I feel a deep responsibility to share what I have learned about hereditary breast and ovarian cancer and BRCA gene mutations; compelled to pay it forward by sharing my BRCA story and spreading risk awareness to women, just like the information was given to me. I have found that a lot of women have heard of BRCA but really don't know exactly what testing positive for a gene mutation means. My decision to have preventative surgeries is what was right for me; however, it may not be right for everyone. Other options for breast cancer risk reduction include taking Tamoxifen and/or enhanced surveillance/screenings. However, there is currently no accurate ovarian cancer surveillance/screening method. I hope that all women realize that knowing their family history and learning how they can stay healthy is really the most loving thing they can do for themselves and their loved ones.

How did I find out all of this information about BRCA?
Most of what I have come to know about my BRCA1 genetic mutation was provided by FORCE (Facing Our Risk of Cancer Empowered) www.facingourrisk.org What is FORCE? FORCE is a nonprofit organization for women whose family history or genetic status puts them at high risk of getting ovarian and/or breast cancer, and for members of families in which risk is present. The mission of FORCE is to improve the lives of these individuals and families. I am currently the Palm Beach County, Florida outreach coordinator for FORCE. Outreach groups provide support, resources, and education. It was the June 2012 FORCE conference that provided me and my sister with invaluable information that helped us make important life-saving decisions. If there is a history of breast and/or ovarian cancer in your family,

you owe it to yourself to go see a certified genetic counselor. Unlike your ob/gyn or primary care physician, a genetic counselor is trained to assess your background, deem if genetic testing is advisable for you, and then administer the test. A genetic counselor knows how to interpret the test results--which is hugely important since you will be making health decisions based on those test results. Plus, if no genetic mutation is found with testing, a genetic counselor will still be able to correctly counsel you as to what your lifetime screening and /or monitoring should be. You may still be at higher risk than the average population.

If you don't know your family medical history, start asking about it now--knowledge is definitely power. Listen to your inner voice; if you suspect that your genes may be putting you at risk for cancer, contact a genetic counselor instead of analyzing it yourself. A genetic counselor is the best first step for someone to take because they will know how to counsel you on what to do.

My husband Jon and I are part of the public relations campaign at Jupiter Medical Center for their newly accredited Breast Center Program (www.jupiterbreastcare.com), which is named after our dear friend Kristin Hoke. Sadly, Kristin succumbed to her disease in June of 2012 at age 42. Jon and I are sharing our story, our face, and our knowledge because we feel strongly about informing as many women, men, and families as we can about hereditary breast and ovarian cancer. Hopefully by doing so, we can help save lives.

*A footnote to my story:
My sister Jan was planning on moving forward with her own prophylactic mastectomy and reconstruction in the spring of 2011. In preparation for that surgery she had a breast MRI in January of 2011. The MRI And subsequent biopsy detected invasive ductal carcinoma (cancer). Her surgery was obviously moved up. Fortunately, the cancer had not spread. However, she has had to endure many additional surgeries due to the reconstruction issues she has encountered.

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