

Cooperative Funeral Fund Inc.

The Final Word on Being BRCA1 Positive..Maybe

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The Final Word on Being BRCA1 Positive ... Maybe

It is hard for me to believe it is almost a year since I found out I was BRCA1 positive. For those of you who haven't read the earlier parts of my story, being BRCA1 positive means I have a gene that makes me predisposed to both ovarian and breast cancer. As I get older, the chances of having either or both increases where the lifetime chance is 85 percent.

For those of you who have read the series on my BRCA1 journey, thank you – and for those of you who haven't, I hope this article will motivate you to look at your back issues. (My previous articles were published in the April, May and October 2018 issues of *American Funeral Director*, you can also read them online at www.americanfuneraldirector.com/mygenes).

When I was asked to look back on my experiences after discovering I had inherited a mutation in the BRCA1 gene, which fights breast cancer, ovarian cancer and pancreatic cancer, I could not believe it had already been a year since my first article. My thoughts are no longer those of anticipation, but rather, "OK, what now?"

I am a new me, looking more like a Barbie doll than a real girl – and not because I have long legs and a small waist. It honestly doesn't freak me out as I look in the mirror while ap-

plying an anti-scaring gel to the area where my nipples once were. I have adjusted to the new look so much that I have a hard time picturing myself *with* nipples.

I took a few pictures before my surgery for that very reason. I hope those pictures never end up accidentally online somewhere. Then again, who cares, a nipple is a nipple except these are *my* nipples, or should I say they *were* mine. Several people have asked, "How are the new girls?" And my favorite, "When are you going to reveal them?" My response is, "When trocars fly!"

Here is the thing: Yes, I had reconstruction surgery – and yes it is very similar to a boob job ... but it really isn't. I don't have nipples, so I don't have the urge to show off my "new girls." It's not that I am ashamed of my new look, it is just really different.

I am proud of what I have done to prolong my life, and like so many other women, I am dealing with

body issues, or as I think of it as a body crisis. Let me explain: Along with a double mastectomy with reconstruction, I had a full hysterectomy, which put me in immediate menopause. For those of you who have reached this stage in your life and for those of you who love a woman going through this stage, it can be challenging. It is hard for those around us to relate to or understand our crazy – well, what others *think* is crazy – behavior. It is frustrating knowing what is coming out of our mouths may not exactly mean what we intended to say. I know many of you out there know exactly what I am talking about – that is, if you are willing to admit it.

My whole life I spoke before engaging any filter. Now I find myself grasping for words as if I am in the early stages of dementia. My dad battled Alzheimer's, and I know there is a possibility that I inherited that gene along with the BRCA1 gene from him.

If he were alive, I would never have let him know I inherited the BRCA1 gene from him. His gentle soul would not have been able to handle it. He was my favorite mush ball. Now, it is my husband. (It is OK if my husband reads this because he is proud of his mushballness). As a funeral director, I am just really good at keeping my inner turmoil to myself, being strong for everyone around me. Who wants a crybaby around anyway?

Although, a good snot-flowing, face-soaked cry is very cleansing. I will never forget the time a 90-year-old woman collapsed during calling hours because it was her son and not her in the casket. After carrying her to a quieter area, I broke down and cried. I was only 20 years old. One of the family members looked at me and said, “Wow, are you crying? That actually makes me feel better.” Um, you’re welcome?

Through this last year of life-altering events, I have met so many amazing people who never let me feel anything but positively. Actually, feeling sorry for myself isn’t in my DNA. My struggle is more physical than mental, at least that is what I have convinced myself. My frustration with my new body is due to the fact that I feel like the Pillsbury Dough funeral girl. I have been athletic my entire life while working hard at staying in shape. I finally reached tears recently, so disgusted with myself and the lack of ability to get my weight gain under control. I felt so unhealthy after doing something so drastic to make myself healthier. I have scoured the internet for the magic pill that will make me go back to the fit and fantastic me. Yeah, yeah I know – I need to be gentler with myself. It isn’t going to happen any time soon unless I get off my lazy butt and stop eating

cannolis while binge watching “The Punisher” or any of the Marvel series. What can I say, the kids got me hooked – on the series, not the cannolis, silly.

I am not obese yet, just overweight. I need to find “the me” I lost when all this started. I need to stop making excuses regarding getting in shape. Life is truly a one day at a time, baby steps, telling your inner voice to chill out, kind of life. We will get there body, soul and mind if we put one step in front of the other (which reminds me of one of my favorite holiday shows, “Santa Claus is Coming to Town”). Sorry, I digress. My point is, finding the strength to make any changes in our lives in anything we do can be hard – especially when you are a funeral director.

Humor is my one superpower that I use to diffuse what ails me. I remember one day in particular, when I was so upset for letting myself go that I started to cry. My husband, seeing my distress, wrapped his arms around me and whispered in my ear, “Oh honey, it’s all my fault ... I make all my wives fat.” Realizing how that sounded, he followed up with a quick, “That didn’t come out right.” Instead of being mad, it was exactly the right thing to say. I laughed so hard I wet my pants, which, don’t get me started, is another condition of my condition. Usually a good tight leg crossing helps, but I couldn’t do it fast enough. It’s not like when you sneeze, you have a longer warning to get into position. When you laugh, it is instantaneous. OK, for some of you that was funny and for some of you, too much information.

Listen, please do not feel sorry for me! After rereading this, it almost sounds like a pity party. It isn’t meant to be. I am just trying to be real and

share myself so that anyone else who is feeling the way I do knows it is normal. It is so easy to be gentle with others and not gentle with ourselves. I know it is an occupational hazard in the death-care industry. Part of our DNA is putting others first. Come to think of it, choosing the radical procedures I did put me first for once. I want to live longer, I want to be healthy and I want to share my story. “I want” is a much stronger mindset than “what I don’t want.” More often than not, thinking of your “don’t wants” will bring them right into your lap. It is some type of cosmic bad karma thing. Maybe I read too many self-help books, I heard somewhere readers are leaders.

The question I often get is, “So did you go bigger?” Hell yeah I did, but not big enough to make extra money on the side or tip over when I walk into a room. My challenge right now is figuring out the right bra to wear. The girls, even though bigger, are shaped a little different than the original ones. I keep meaning to go to Victoria’s Secret and get measured (I heard somewhere they do that). I think the new girls deserve a little lift, don’t you?

At this moment in time, I am working on becoming a healthier me – and hell yes, I would do it all over again, even knowing what I didn’t know then. Ultimately, I chose to do something that people tell me they could never do. In my mind, what I did was an absolute no-brainer. As I look back, yes there was pain and some really scary moments. However there is a resounding feeling of peace, contentment and confidence in what I did. What sticks out most are not the painful moments but the ones that made me wet my pants from laughter. Even though the peeing part sucks, the laughter is awesome.

While I hope you found my story uplifting, I hope part of it rang true with you and in some way you connected to it. My goal is to make you cry from laughter along with inspiring you to find the strength to make necessary life changes. For me, my BRCA1 story is my story – it is what now makes me me – no nipples and all. •

To read the first three parts of
Ann Marie’s story, visit
www.americanfuneraldirector.com/mygenes