Cooperative Funeral Fund Inc.

## My Genes Fit Me: Part 2

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By Ann Marie St. George

## My **Genes** Fit Me Part Two

Funny, how it's so easy to procrastinate when you need to make difficult, life-changing decisions – like maybe prearranging one's funeral, wink-wink.

t's as if I don't make the decision, the problem will go away. I am sure a few of you know exactly what I am talking about. A very close friend of mine found out she was BRCA1 positive and within three months has already had the surgeries necessary to save her life. Then there's me, trying to figure out how to plan everything around my work and family schedules. If I keep it up, I could possibly schedule my surgeries for 2063 – putting me at about 100 years old. (Now you know what year I was born ... lol.) When told one is BRCA1 positive – which is when the gene that fights breast cancer, ovarian cancer, pancreatic cancer and prostate cancer does not work, making my risk to having any of these cancers (except prostate of course) a great deal higher than the general population – it would be easy to ask, "Why me?"

But here is the fact: All our inherited traits are passed down through genes. Every one of us has two copies of every gene, one from each parent. Basically, the genetic traits of each parent have a 50 percent chance of being passed on to you. For example, I have red hair because both my parents have the red hair gene. It would be impossible if only one of them had the gene. Unfortunately, it took only one of my parents to have the BRCA1 gene for me to inherit it. I am presently working on figuring out which parent it was from since my father is deceased. With all these crazy advancements in genetic engineering and manipulation, my biggest fear is that a week after my surgery they miraculously discover a way to tweak the BRCA1 gene making the surgery I just had obsolete. Funny but not funny. Back to the "Why me?"

Honestly, for me, asking "why" is a waste of time. The truth is, I am BRCA1 positive, so now I need to suck it up and deal with it, something I learned from a Scottish/Irish immigrant parent. When I was a kid my not-so-favorite saying was, "If you don't stop crying, I will give you something to really cry about." Ironically, that threat has helped me put things into perspective. Sadly, I have zero tolerance for whiny people. My brain goes right to "geez just get over it already, would you?" I feel all these nuances of my childhood have helped me to stay a little more grounded and introspective than most people. For a dose of reality, working around so much death doesn't hurt either. I just need to move forward and figure this thing out.

Regarding researching the right doctors ... What other way is there than googling through the internet? We all know this googling thing can truly be a cluster#\$@%! of information. It made me pause to think about the consumer out there trying to find the right funeral home. We really need to step up our game when it comes to our social media presence on the internet, starting with our websites. Please take a step back and honestly assess your website or have someone vou trust give vou an honest opinion. You don't want consumers thinking your site is a cluster#\$@&% – it's a real turnoff.

Sorry, I digress. My husband tells me I'm like a puppy who sets out on one path, and upon seeing a squirrel, I am easily led down another. I really can't argue.

I miss the days when we used encyclopedias that our parents bought at the local grocery store to help us with school research projects. The unsettling thing is that most of the information in them was already outdated by the time they were printed, sort of like the present-day daily newspaper, which is quickly old news due to our far-reaching internet.

Every so often we wouldn't have the letter series encyclopedia we needed for our school projects, so we rode our bikes to the neighborhood public library praying no one would steal our bikes while we were inside. Maybe, I don't miss that part of those days. So, since we are beyond the "good ol' days," I dug into some good ol' fashioned Google research instead of riding my bike anywhere, though I really could use the exercise.

Ultimately here is my dilemma: Do I want to start with the upper-half doctors or the lower-half doctors? There is so much information, and I quickly found myself confused and overwhelmed. Frustrated, I started over and went back to the information I was given by my genetic counselor.

Looking through my notes, I found a website that connected me to a local support group: www.facingourrisk.org/get-support. Here I was able to sign up for more information and guidance. I instantly received an email, and within days, a phone call from someone just like me. Bridgett

Now, I'm thinking it is only 8 in the morning. After the second time you felt like you were going to pass out, why didn't you think there was a problem? What the crap, doesn't she know I've never done this before and I'm not feeling confident I am in safe hands right now? She turns around and sits next to me and motions to someone else in the room. That woman picks up the phone and calls someone else in the hospital. Right about that time I'm starting to feel like running for the door they roll in a stretcher and roll Ms. "I might faint" out the door.

OK! I suddenly hear another voice casually say, "Hey Dave, you want to put the IV line in this patient?" I'm looking over at whom I think might be Dave and wonder if Dave is really the janitor moonlighting as the IV line guy. Using my wit and charm, I nonchalantly ask "Dave" a few questions to see if he has done this, "putting an IV line in thing" before. Dave appears to know what he's

## To read the first part of Ann Marie's story, visit www.americanfuneraldirector.com/genes

put me in touch with two worldrenowned surgeons: One removed the breasts, and the other reconstructed them. The second's claim to fame was the best "gummy bear" implants you will find anywhere. As much as I really wanted those gummy bears, the distance from home was not reasonable, so I continued my search.

As I carried on my research, my family doctor sent me for more tests to make sure I positively did not have cancer. First up, she scheduled me for a breast MRI. Um, yeah, I didn't know there was such a thing either. The morning of my MRI, as I answered a battery of questions, the practitioner taking care of me suddenly whispered, "I feel like I am going to pass out. Wow, this is like the fourth time today." doing, so I calm myself down by chuckling to myself - realizing I am totally in a "Seinfeld" episode. Then Mary, who has replaced the "fainter," asks me what kind of music I would like to listen to while doing the MRI. Hmmm - what kind of music goes with putting your breasts in two holes and not being able to move for 30 minutes? Disco, rock or easy listening? I don't want to blur the MRI with my bee-bopping, so I choose Michael Bublé, who should chill me right out. But instead of hearing Michael's smooth voice, Frank Sinatra crooned in my ear. What the heck? Hey, not all things go smoothly – and that morning was one of them. Fortunately, and ultimately, the most important thing was they did not detect any signs of cancer. Yeah!!

After a few more random blood tests and a transvaginal ultrasound (thought I was going to wet my pants on that one), there are no signs of cancer. Can I get an "Oh yeah!" With this behind me, I feel clearheaded about finding the right doctors. I realized that right in my backyard (within two hours) is a world-renowned cancer research hospital: Roswell Park Comprehensive Cancer Center (www.roswellpark.org/). Now, I don't have cancer, but why wouldn't I go to the experts who can detect and treat this disease? While searching through its website, I found the right-for-me Roswell doctors.

The hardest part of walking into Roswell? Almost 22 years ago to the day, my sister died of brain cancer in what was then called the Roswell Park Memorial Cancer Institute. My apprehension and flashbacks to a time that didn't feel so long ago were lifted as I looked around at the newly renovated hospital. Wow, it wasn't even close to that oppressive place I once remembered. The craziest thing is the hospital still had me in its system as I was my sister's bone marrow donor, like I said, 22 years ago.

I can't say enough about the compassion and awareness everyone I met that day had, from the woman validating my parking; the gentlemen that gave me a flashing pager as I waited my turn; the woman who took all my information; the receptionists in each clinic; the doctors, nurses and technicians and finally the parking garage attendant who greeted me with a warm smile and an awesome sense of humor while helping me figure out which freaking slot to stick my validated ticket in.

Ultimately, the deciding factor for me was the fact that a team of specialists will perform both surgeries in one sitting. So, instead of having two four-to-six-week recoveries, it would be one recovery period. I will be under the phenomenal care of three amazing doctors/surgeons: Dr. Stacy Akers (gynecological oncologist), Dr. Helen Cappuccino (breast oncologist and yes, that is her real name) and finally Dr. Robert Lohman (plastic reconstructive surgeon).

After much coordination between my work and family obligations and all three doctors, my surgery is scheduled. Now as I wait, I need to make sure I am mentally and physically ready for what lies ahead. This probably means staying the heck off of the internet.

Thank you for letting me continue to share my journey, and I look forward to sharing my surgical escapades and the ensuing recovery. I hope for more "Seinfeld"-esque encounters – they make for a way better story. •

