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## BRCA JOURNAL: CHAPTER TWO

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(Chapter two of five. Read chapter three [here](#))

#### **Screening**

After testing positive for the BRCA gene, I knew that I had to take action to protect myself. I did not hesitate to begin the new screening regimen my doctor recommended and scheduled my first tests almost immediately. In the beginning, I felt empowered; but then the test results came back. None were positive but several were “abnormal,” requiring follow-up tests. Everything wound up being fine, but it was stressful. The mammogram had to be repeated, the MRI had to be repeated, a benign cyst formed on my ovaries the same time I was scheduled for my ultrasound and so that came up abnormal, a spot on my liver showed up on the CT of my pancreas. Everything found wound up to be “nothing,” but it was a stressful way of beginning my life as a BRCA2 patient. I knew that everything was fine, but you can’t help but worry when the whole point of the test is to look for cancer which you know you have an increased risk of developing. I got through those tests as I do all of my tests now: with a sense of resolve and knowing that a little bit of anxiety is well worth the opportunity to catch cancer early so that I have a better chance of surviving if and when it does rear its ugly head.

#### **Preventative measures**

On New Years’ Eve 2006, I found out I was pregnant again. During that pregnancy my husband and I began to discuss the option of a prophylactic oophorectomy (removal of my ovaries and fallopian tubes) and when I should have it done. I met with my genetic oncologist and discussed it several times during my regular visits with my OB/GYN. The effects would be great. My oncologist called it “the best bang for your buck” because if I had the surgery, I would almost completely eliminate my risk of ovarian cancer and would also decrease of my risk of breast cancer by about 50%. Going on tamoxifen for five years would decrease my risk of breast cancer by another 45-50%.

My daughter was born on September 4, 2007. Even with the craziness of the birth of a baby and making sure my older two were adjusting to a new year of preschool, almost immediately I began questioning whether I should have my ovaries out. I wasn’t afraid of the surgery -- it is a simple procedure that is done laproscopically -- but once I had my

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ovaries out, I would immediately go into menopause.

The thought of going into menopause was almost paralyzing. It kept me up at night. I wasn't worried about hot flashes; I could deal with those. I was most concerned about mood swings and irritability. I have witnessed some pretty intense outbursts from menopausal women I know. And I would not be going through menopause gradually like they had; my menopause would set in immediately and more intensely. I worried that I could really be hurtful to my children and my husband.

Naturally, I discussed my anxiety with my husband. He was very much a part of my decision-making process. As with my pregnancies, we felt like it was our BRCA2 mutation, as it greatly affected us both. However, he admitted that he didn't understand my anxiety over going into menopause. "Isn't it something you are going to go through anyway?" he asked. He didn't get it. It wasn't his fault, he just didn't get it. So I discussed my anxiety with my friends. Some thought I would be fine; others, including some who had gone through menopause, urged me to do everything I could to avoid it at such a young age.

One friend suggested that I call her sister-in-law, who, after testing positive for BRCA2, had a prophylactic hysterectomy and mastectomy. Being only a few years older than me, she would be able to talk to me about what it was like to go through sudden menopause. I couldn't believe what I had just heard. A prophylactic hysterectomy and mastectomy? And she didn't have cancer? I believe I called her "hardcore." But she was the only woman I knew who had chosen to remove her ovaries (and then some) prophylactically.

My friend's sister-in-law was a huge help. She told me the hardest part of the whole experience was the decision-making process, that she went back and forth a million times before she finally made the decision to have her hysterectomy and mastectomy. The day she had her hysterectomy she was put on a low dose anti-depressant known to help menopausal women. She has felt great emotionally and has had very few hot flashes as a result. Like most high-risk women, she hoped to avoid taking hormone replacement therapy because it can increase the risk of developing breast cancer. I had no idea that antidepressants could be used to help with menopause. It was an example of a lesson that I have learned over and over again since then: when I reach out to others who have gone through the process before me, I always learn something new.

I was going to end the conversation there, but she began to tell me about her prophylactic mastectomy. She told me how good she looked now that her breasts were "re-done" and she was thinner. She told me that immediately following her mastectomy, a plastic surgeon reconstructed her breasts using fat from her buttocks. It's funny to me now that I've done so much research on the topic, but at the time, I had no idea that you could have your breasts reconstructed at the same time you had them removed. I certainly didn't know that you could use your own fat to reconstruct your breasts...

My friend -- I now consider her my friend, not just the sister-in-law of my friend --

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admitted that it was a stressful decision to have a mastectomy, but she told me that she feels great, looks great and lives with a complete sense of relief. Though she knows she could be hit by a car tomorrow, she walks a little lighter because she has done everything in her power to prevent cancer. She gave me some great advice on books to read about mastectomies, reconstruction and sudden menopause. She also told me about an organization she was involved in called FORCE: Facing Our Risk of Cancer Empowered ( [www.facingourrisk.org](http://www.facingourrisk.org) ). It was the only group I could find to help people like me, who don't have cancer but are at a high risk of getting it.

After talking to my friend, I began to think a mastectomy could be my salvation. Because a mastectomy would almost entirely eliminate my risk of breast cancer, I could avoid having my ovaries out. I had only considered having my ovaries out because it would lower my risk of breast cancer; I wasn't worried about ovarian cancer because none of my relatives had had it.

So I began to do my research and talk to doctors. I learned everything I could about mastectomies and reconstruction. I learned about a procedure called a DIEP flap reconstruction that seemed perfect for me. First a breast surgeon would remove all of my breast tissue; then a highly skilled plastic surgeon would use the fat and skin from my abdomen to recreate my breasts. Because my own tissue was being used, my breasts would have a natural look and feel. It sounded like a win-win -- I could have my breasts done and get a tummy tuck.

But like they say, "Ignorance is bliss." My oncologist referred me to a breast surgeon and a plastic surgeon who could perform the DIEP flap reconstruction. When I met with the plastic surgeon, I learned that if I chose to have a mastectomy, it would not be like having my breasts "done." For one thing, the surgery for the mastectomy and DIEP flap reconstruction I was considering would take approximately 15 hours. I would have to spend a day in the ICU and a week in the hospital before a painful six-week recovery. There would be scars on both my breasts and my abdomen. But I wasn't completely deterred. I could avoid menopause!

When I met with the breast surgeon, she agreed that a prophylactic mastectomy would be appropriate given my BRCA2 mutation and family history. But she adamantly insisted that I also have my ovaries removed because of my increased risk of developing ovarian cancer. She said that because of the difficulty of detecting ovarian cancer, 70% of women don't catch it until it is in an advanced stage. To my chagrin, my genetic oncologist agreed. They both felt that they could catch any breast cancer that might develop early enough to give me a good prognosis, but if I developed ovarian cancer, my chances of survival wouldn't be great.

I planned to seek other medical opinions before making any final decisions about proceeding with either an oophorectomy or mastectomy, but in the meantime, I decided I should tell my father about the prophylactic options I was considering. I knew he wouldn't be happy. I was pretty sure he would think having a prophylactic mastectomy was a crazy idea, but then again, so did I at first. I didn't really want to argue with him,

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but I figured that if I told him what I was considering and let him in on how much research I was doing, then by the time I did have a mastectomy, if that was what I decided to do, he would be comfortable with the idea and would support me.

When I told my dad, I got the "WHAT?!" reaction I'd been expecting. At first, he thought I was being impetuous out of panic. But we spent some time talking. I told him about the doctors I had already seen and the ones I was scheduled to meet. I explained that I certainly didn't want to have a mastectomy, but felt it was a reasonable option considering my risks. "Well, what exactly are the risks?" he asked. When I explained that my risk of breast cancer could be as high as 87%, there was a long silence as the words sunk in. I knew he was upset. He had stood by my mother's side during her grueling fight with cancer, but he just couldn't agree that it was a good idea to have surgery when I was perfectly healthy. He asked me, "Can't they just screen you? I thought you were having MRIs done." "Yes," I said, "I could just continue with my screening, but after much soul-searching, I have decided that I am not comfortable with that option because I don't want to 'catch' cancer, I want to avoid it." He then said what many others have said to me when they heard what I was considering: "But if you wait five years, they'll probably have something for you . . ."

I had to remind him of my reality. "Five years from now, I will be forty. Mom didn't make it to forty. If I don't live another five years, then all the science in the world isn't going to help me one bit." Not even the lawyer in him could argue that point. We have had many more conversations on the topic since then, and I am glad that I let him (and others over time) in on my plans so that they wouldn't come as a shock.

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**Michelle McBride** lives in Chicago with her husband and three children. Michelle has helped make SU2C a reality and been instrumental in aligning SU2C with MLB. She sits on the boards of two cancer research foundations: [Little Heroes](#) and [Noreen Fraser Foundation](#). Michelle dedicates this piece to her husband and three kids.