

# Genetic testing can help determine breast cancer risk

By Markian Hawryluk / Published in the Bend Bulletin Newspaper on 11-24-05

Knowledge can be a wonderful asset. It can also be a terrible burden. In the 1990s, researchers discovered that genetic mutations found in one out of every 500 women substantially increase their risk for breast cancer. Women with a mutation in the BRCA 1 or 2 genes have an 80 percent to 85 percent chance of being stricken. A genetic test can now determine which women have the mutation. But many struggle with the decision to have the test and must carefully weigh the ramifications of finding out. For two Bend women, the decision of whether to pull open that door and get a vision of what their fate may hold in store for them may have been the toughest of their lives. Shari Harris-Dunning grew up knowing she was at high risk for cancer. "That was always the cloud hanging over my head since the age of 10," she says. "It was always 'We've got cancer in our family.'"

## **In the family**

Her family is of Ashkenazi Jewish heritage, an ethnic group with a high prevalence of the genetic mutation. Her mother and aunts all had breast cancer. Three years ago, her mother also developed ovarian cancer and had the genetic testing done. It confirmed the mutation. That left Shari unsure of how to proceed. "It really became incumbent upon me to think about what I needed to do," she says. "I kind of sat on it for a while because the repercussions of a woman testing positive are pretty staggering." Cindy (who declined to be identified by full name) was diagnosed with breast cancer in 1994 at the age of 39. Her great-grandmother, her grandmother, her aunt and her mother all had breast cancer. At the time, the genetic test was only being done at research facilities. In 1995, her mother tested positive for the mutation. Cindy and her sisters also had to make the decision of whether to be tested. "For me, the test was empowering," she said. "Knowing something is, I think, less scary than not knowing. It might have been different if I had taken the test before my breast cancer."

Seeking counsel, both eventually wound up at the office of Barb Pettersen, a genetic counselor in Bend. She looks for clues in a patient's history to determine how likely they are to have such a genetic mutation, and then she helps them sort through the issues they must consider before

being tested. The test is a modern-day Pandora's box. Once you know the results, there's no going back,

“It’s important to go through the genetic counseling process before you stick out your arm and have your blood drawn for genetic tests, because the results are forever,” Pettersen says. “You have to go through the process and make decisions about what you would do with the information. Is it worth it for you right now to get this information? Do you feel empowered or is this going to affect you so adversely psychologically, that it's not right for you right now?”

Many times women will come for the genetic counseling sessions, process the information, and decide they're just not ready to know. Some return after two or three years to get tested. Others never do. If they do test positive, they have more decisions to make.

“We start screening much earlier in people with these mutations, as early as age 25 to 30,” Pettersen says. “They are beginning to use MRI instead of just mammography because the MRI is much more able to pick up certain breast cancers that can be missed by mammography.” Women are strongly encouraged to have their ovaries removed by age 35 or after deciding they will have no more children. Removing the ovaries reduces the risk of ovarian cancer in these women by 96 percent and the risk of breast cancer by 50 percent.

Some opt for prophylactic mastectomies, choosing to take the most aggressive action to protect their lives.

### **Next generation**

And then there's the inevitable question of what to tell their daughters. A woman with the mutation has a 50-50 chance of passing on the mutation to a daughter. Both Cindy and Harris-Dunning have two daughters. “What do you do with your teenage daughters? Because they have the test, but they don't have a follow-up or a protocol for the next generation,” Cindy says. “That’s always the first step: to find out why you want to know and what the information will do, find out everything to see if that's the right thing for you to do, because it isn't for everyone.” Harris-Dunning's daughters are younger, well below the age where she would consider having

them tested. She opted to wait on her own testing and undergo frequent screening instead. "I didn't really want to test initially. I wasn't ready for that knowledge and to move forward with it," she says. "I wasn't ready to deal with surgery. I had to wait until emotionally I was at that point where I could handle it." Then six months ago, her mother died from ovarian cancer. "Once that happened, I had a real mind shift, that this is serious stuff and I don't want to end up like her," she says. "I decided to test in the middle of the summer."

She and her husband began to prepare for the emotional impact of the results. She came across FORCE, or Facing Our Risk of Cancer Empowered, an Internet support group for women staring down the same decision and for those who had already opened their own doors. "That's a really powerful group of people that are very savvy and knowledgeable and have been there," Pettersen says. "So it's even better than getting the information from a genetic counselor that may not have walked in these people's shoes. The people at FORCE have walked that path." Coming to terms the site helped Harris-Dunning continue the process she had started with Pettersen. She made the decision she would get tested. She wanted to make sure she was around for her kids. "I had prepared reasonably well, but it was just, 'I'm doomed,'" she says. "You sort of put yourself in that frame of mind." Only she wasn't prepared for the news she would receive. She tested negative.

"It was almost sort of shocking, because we, both my husband and I, geared ourselves and when you're sitting there and you're waiting for the results, and you say, 'OK, this is it. It's going to be this way.' And then when it's not, it's pretty mind-boggling," she says. "It's bittersweet to go from one to the other."

It also means her daughters are in the clear. They could not have inherited the genetic mutation, and now have the same risk as any other woman. The same level of risk their mother now faces. Cindy also decided she needed to know. "I have taken the genetic test and it's positive," she says. She underwent surgery to have her ovaries removed. Now she's left with more unanswered questions. "I'm kind of in no-man's land in terms of figuring out what to do with follow-up and my daughters," she says. "Technology is a little bit ahead of the practice of medicine." One of her daughters has spoken with Pettersen. Neither has been tested yet. Now they will face the

same decisions, the same emotional struggles as their mother. Each has a coin-flip's chance, 50-50 odds of inheriting the mutation.

“That’s the power of this,” Pettersen says. “It can tell people whether we really need to watch you more carefully, or you're at average risk, go home and celebrate.”