The Power of Angry Women

Part One

It all began while watching the Today Show from a hospital bed. It is 1991, Patti Goodall is a 38-year-old mother with 3 and 5-year-old children at home. She has been admitted to the hospital for complications from her first chemo session.

To pass the time, she is flipping through the TV channels and lands on the Today Show. Someone talking about breast cancer catches her attention. Elenore Pred, co-founder of Breast Cancer Action is on television.

Pred had been diagnosed with breast cancer in 1981. She had a recurrence in 1988 and was angry that in all those years, there had not been any progress in how the disease was being treated. She was also angry at the increasing number of young women being diagnosed with and dying from breast cancer. She was planning a protest rally for Mother’s Day in San Francisco, CA. After Patti got home from the hospital, she called information, got Pred’s number, and gave her a call.

Patti has a support group meeting coming up the next week. She is one of their newest members. She had been reluctant to join the group thinking that it would be a “touchy-feely” experience, something that didn’t suit her. Sherry Kohlenberg, another young mother with breast cancer, convinced her to go. What she found was a group of women who were very informed.

“It was not a bunch of women sitting around whining. They were very knowledgeable. They were reading [scientific] journal articles. They were talking about their ability to have children after breast cancer. They were talking about genetics;” remembered Goodall. “I thought ‘Wow, these women are on top of things!’”

Patti decided to pitch the idea of hosting a rally to the group. “She was red-faced and angry, saying that there’s not enough money for breast cancer research; we need to protest, too. Let’s do a Mother’s Day rally!” recalled Mary Jo Kahn, a fellow support group member.

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“We thought, ‘We can do this. We can start something like this in Virginia to raise awareness, to demand more money for research and to be the voice for Virginia women affected by breast cancer!’” said Goodall.

Every member of the support group agreed. They had two months to plan. They lined up speakers. There was a notice in the paper. They recruited their children to make signs. About 50 people showed up for the rally. Doctors and nurses were there. A reporter was there.

“Our children had made some posters that were on the front page of the next day’s newspaper. As a result of the rally, The Richmond Times-Dispatch did a whole story on the current state of breast cancer and our nascent organization’s efforts to eradicate it. We had met our first goal: to raise awareness.” said Kahn.

The rally ignited a spark in five of the support group members. Patti Goodall, Sherry Kohlenberg, Mary Jo Ellis Kahn, Judi Ellis and Phoebe Antrim decided to form VBCF.

“After the rally was over, the five of us knew we had another goal yet to meet. We needed to make sure enough research money was available not just to make progress on breast cancer, but enough actually to eradicate the disease. Most of us had young children. What we were fighting for was prevention.” said Kahn.

Part Two

Mary Jo Ellis Kahn is no stranger to breast cancer. Her mother was diagnosed with breast cancer at age 39 and died of it eight years later. In 1989, when Mary Jo was 39, she found her own breast cancer. While she was in the hospital undergoing a mastectomy, her sister, Judi Ellis, was diagnosed. She was 41. This led two more of their sisters to have prophylactic mastectomies in their mid-30’s.

Mary Jo remembered, “When my mother was diagnosed in the ‘60s, the words breast and cancer were almost never said in public and people whispered them in private. Twenty years later, some things had changed. Cancer could be discussed in the open, even breasts could be, but breast cancer was still whispered as if it were something embarrassing to have. Meanwhile, the lifetime risk of having the disease had risen steadily from 1 in 20 when my mother was diagnosed to 1 in 9 when my sister and I were diagnosed in 1989. Even with this startling rise in incidence, there was no press coverage; there was no public outcry, there was no special outlay of research money to combat this disease. Breast cancer was a silent epidemic.”

This was about to change in a big way. Find out what happened next at www.vbcf.org/angry-women.
What You Need to Know: At Home Genetic Testing

The at-home DNA testing company, 23andMe, recently had their BRCA home test approved by the FDA. While some experts believe this is a great step towards transparency and helping patients understand their disease risk, many others are concerned that this testing will lead to greater misinformation.

The benefit to this at-home test is that it increases access to genetic testing. This testing is now fully covered by most insurances, but the person being tested must be determined “high risk.” As we know, not everyone has access to health insurance and some people with insurance may not fall under the guidelines of “high risk,” but still want to know their genetic risk. This kit helps make that knowledge possible. John Quillin, Ph.D, a genetic counselor from VCU Massey Cancer Center, sees some benefit: “Because of limited family structures and inheritance through men in the family, many women with hereditary breast cancer might not know they are at risk. Broad-based, accessible, affordable, direct-to-consumer testing may help increase access and awareness.”

A major concern with the test: Consumers are tested on “the three mutations in the BRCA1 and BRCA2 genes that are the most common in the Ashkenazi Jewish population. Those mutations are not the most common BRCA mutations in the broader population.” For context, there are “more than 1,000 known BRCA1 and BRCA2 mutations.” This means that your average consumer will take the test at home, it will come back negative for those three mutations, and they will believe themselves “safe” from breast cancer.

Genetic testing is a complicated process, which is why there are genetic counselors dedicated to helping people decide whether or not to get tested, and what to get tested for. Here’s one genetic counselor’s take on the decision:

“‘[T]he problem comes in when a patient may not have an understanding of their results and potential implications for their health,’ [Karen] Grinzaid said. ‘It puts them in a position of interpreting results and finding their own resources and puts their...primary care physician, in a position of explaining results they may not understand.’”

Different mutations within the BRCA genes are more common in people with different ethnic backgrounds, and there are other genes to look at besides BRCA (including CHEK2, PALB2, etc). Genetic counselors know this information, so they can point a person in the correct direction as to which tests to get. Genetic counselors can also help patients figure out next steps when they are clearly high risk due to their family history, but get negative results or results of mutation of unknown significance. Dr. Quillin highlighted another concern: “...while the FDA affirmed the validity of [23andMe’s] test results, 23andMe does not run additional confirmatory testing of positive test results, which typically happens in a clinical diagnostic laboratory.”

Genetic risk is not the only factor in developing breast cancer, in fact only about 10% of breast cancer diagnoses are known to be affected by genetic risk. No matter your results on a genetic test, you can reduce your risk of breast cancer by exercising, eating a healthy diet, and not smoking. If you are interested in learning more about your genetic risk for breast cancer, talk to your doctor about connecting with a genetic counselor.

To see this article with source notes, please visit www.vbcf.org/genetic-testing-at-home.
Medical Cannabis Success: What’s Next?

VBCF’s volunteer advocates had a major victory in the 2018 General Assembly session with passage of “Let Doctors Decide” bills in both the House and Senate allowing doctors to recommend the use of cannabidiol oil or THC-A oil for the treatment of any diagnosed condition or disease. Governor Northam signed these bills into law on March 9, 2018. VBCF championed this legislation because we believe breast cancer patients should have access to all potentially useful tools during their treatment journey, including medical cannabis.

The new law goes into effect immediately. It provides an affirmative defense for possession, but does not make possession legal. A patient or their caregiver would have to present an official written certificate signed by a licensed medical doctor if they were stopped by law enforcement or in a court of law as their defense for possession of the oil. It is important to note that physicians will recommend the oils, not prescribe them as they do with traditional pharmaceuticals. “Prescribe” is reserved for FDA-regulated products, and legally means to write a prescription on a DEA-numbered prescription pad.

The law also expands access to Virginia’s regulated medical cannabis program once it becomes operational. Virginia approved a regulatory program for the in-state production of medical cannabis oil in 2017. Five providers initially, one per Health Service Area, will grow, extract, dispense and deliver the medical cannabis oils. These licensed providers are called “pharmaceutical processors” in the Code, and are simply vertically-integrated dispensaries, meaning everything from growth through dispensation is done on one site by one provider. Once operational, patients will register with the program and then be able to fill their recommendation at one of five “pharmaceutical processors” in Virginia.

This article is excerpted from NORML VA’s website. Additional detailed information is available at www.vanorml.org/faqs.