

# Calm Water in a Sea of Uncertainty

By Melanie Rome

**G**enetic counselor Joyce Seldon helps her patients through one of the most stressful experiences they may ever face—finding out whether they carry a gene that significantly increases their risk of cancer.

Entire families, even future generations, can be impacted by the outcome of genetic testing. And Seldon serves as calm water in this sea of uncertainty, providing solace and advice, sharing prevention strategies and offering a shoulder to cry on.

“Genetic testing is not just about the individual, it is about the family as well,” said Seldon, one of two genetic counselors in UCLA’s Family Cancer Registry and Genetic Evaluation Program at UCLA’s Jonsson Comprehensive Cancer Center. “It’s like when you throw a rock in the water. There is a ripple effect.”

As one of only about 2,000 genetic counselors nationwide, Seldon’s job is both complicated and rewarding. She works as part of a health care team providing information and support to patients who have family members with cancer and who may themselves be at risk for developing the disease.

For patients enrolled in the family cancer registry, simply deciding to find out whether they are at risk for certain forms of cancer can be a difficult decision. However, Seldon says that the vast majority elect to know.

“I think it’s always better to know,” Seldon said. “Then you can take steps to protect yourself if you are at risk.”

According to Seldon, the presence of certain genes does not automatically mean a person will get cancer. Rather, people with these genes have a significantly increased risk of certain forms of cancer when compared to those who do not have such genes.

The family cancer registry tests for the genetic predisposition of many different cancers. The two most common tests determine the presence of genes that may increase the risk of breast and ovarian cancers as well as hereditary colorectal and uterine cancer.

Once a patient decides to get tested, it is Seldon’s job to inform them of the results. Seldon said that test results can be positive, negative or even “somewhat ambiguous.” Providing test results to anxious men and women is not always easy, but the news isn’t always bad either.

“It’s very nice to give test results that are true negatives, as when there is a genetic risk in a family but the person taking the test doesn’t have it,” Seldon said.

On the other hand, when a person tests positive for a cancer-related gene, it can be almost too much for them to absorb.

“When I give these results, I sometimes see that overwhelming look in their eyes, their realization of what may be ahead, a diagnosis of cancer, or the prospect of surgery,” Seldon said. “And for parents, you definitely see worry in their eyes for their children. So

those results can be difficult to give.

“There’s good and bad. And thankfully, it’s not always bad news.”

After informing a patient of their test results, Seldon then provides support in helping them cope with the news, as well as guidance in making what can be very difficult decisions.

Seldon says these decisions are as varied as the people she counsels.

For example, a woman who tests positive for the genes related to breast and ovarian cancer might choose what is considered an extremely invasive option, a double mastectomy or removal of her ovaries. This can be true especially if the woman has lost her mother to either of the diseases. On the other hand, if a woman has observed a family member successfully battle cancer she might opt, instead, not to surgically remove her breasts and ovaries, but to be screened often and be extremely watchful for signs of cancer.

In addition to the family experience, other factors such as age, attitude and values can influence a patient’s decision. For one woman, her breasts might be a symbol of femininity and sexuality, something she wants to hold onto. For another, however, they may seem like ticking time bombs that are better off removed.

Seldon has observed that when she counsels patients there are “a lot of things going on.”

“You can’t generalize. Everyone is different,” Seldon said.

**A**woman with advanced ovarian cancer whom Seldon counseled decided to see whether she carried the gene associated with the disease because ovarian cancer seemed to run in her family. Her mother, grandmother and aunt all had it. The genetic test revealed that she did indeed carry the gene.

Seldon said the woman was relieved to finally know the truth. She decided it was important to pass on the results of genetic testing to other family members, so they could be aware of their risk for ovarian cancer and take measures to protect themselves.

In another instance, a woman who had breast cancer twice and had a family history of the disease decided to get tested. The tests revealed that she, in fact, carried the gene associated with breast and ovarian cancer. As a result, the woman had her ovaries removed. When the surgery was performed, doctors discovered that she had already developed ovarian cancer. She called Seldon with the news.

“I’m sorry,” Seldon told her.

The woman, however, was very upbeat.

“Thank God they found it when they did,” she told Seldon. “Had I not had the genetic testing, it might have been too late. I had no signs, no symptoms. I think you may have saved my life.”

While Seldon doubts that she actually saved the woman’s life, it did remind her just how powerful genetic testing can be.

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“Even in the grimmest of circumstance, having ovarian cancer, it was still something she felt we had helped her with,” Seldon said. “I do think what we do here is very important. I get to work with a lot of really great patients and it feels good to know I’m helping them.”

Dr. Patricia Ganz, director of Cancer Prevention and Control Research at UCLA’s Jonsson Cancer Center, said Seldon is unique in that her interests involve both counseling and research.

Currently, Seldon is involved in several different research projects. They include the Ovarian Cancer Prevention and Early Detection Study; the Study of Tamoxifen and Raloxifene (STAR), a breast cancer prevention study; the Selenium and Vitamin E Cancer Prevention Trial (SELECT), the first study to try to determine whether selenium and vitamin E can prevent prostate cancer; the Tam-MRI study, a clinical trial that involves the use of tamoxifen and breast magnetic resonance imaging (MRI) to monitor changes in breast tissue over time; and a ductal lavage trial to examine new methods for early detection of breast cancer.

As for her decision to become a genetic counselor, Seldon says it resulted from an epiphany.

“I was reading descriptions for graduate school and I came across it (genetic counseling) randomly,” she said. “It wasn’t as though I was searching for it. I read the description and said to myself, ‘This is it. This is what I want to do.’ I want to help people. I enjoy science. I enjoy genetics. It just clicked.” ★

