

A Place to Go for People at High Risk for Cancer

UCLA's Familial Cancer Registry provides support and information for high-risk families.

Genetic testing for susceptibility to cancer is a mixed bag. It can lead to peace of mind, improved lifestyle and diminishing one's chances for getting the disease. It can lead to depression, anger and alienation.

"For the great majority of people, genetic testing for cancer is a highly positive experience, even when it reveals an above average likelihood for the disease," says Dr. Patricia Ganz.

Ganz directs the Familial Cancer Registry at UCLA's Jonsson Comprehensive Cancer Center, where people with two or more close family members who have or have had the same type of cancer can come to discuss participating in various research programs, experimental cancer treatments and — if they have a particularly strong family history of cancer — free genetic counseling.

Genetic testing is an option, not a requirement, for registry members. A person accepted for genetic testing — which can indicate a propensity for getting cancer — is assured of confidentiality at the registry.

"We guarantee none of the information we have will get into a patient's medical records or will be available to health care providers, insurance companies or anyone else without written authorization from the patient," Ganz says. "We hold a certificate of confidentiality from the National Institutes of Health, which is an arm of the federal government, making it illegal for any registry records to be subpoenaed or acquired by anyone not specifically designated by the patient."

Currently, genetic tests are available primarily for breast, ovarian, uterine and colon cancer, but persons with family histories of other cancers also can join the registry.

"Our primary goals," Ganz says, "are to counsel people at high risk for cancer as to their best options, including lifestyle changes, dietary modification and the possibility of contributing to both genetic and non-genetic cancer research in ways that may help them and others with cancer."

Among the registry's specific goals are:

- ❖ To enroll individuals and families who may share a possible genetic risk of cancer.
- ❖ To inform qualified members about genetic testing for cancer, and its appropriateness for registry members or members of their families.
- ❖ To provide members with results of genetic testing and to provide counseling and, if appropriate, psychological support.

- ❖ To develop information on how genetic testing affects a person's health behavior and interpersonal and family relationships.

About half the registry's members opt for genetic testing. Because they are eligible only if they have a strong history of the same kind of cancer in their family, the results are frequently positive, indicating a person does have the mutation that makes him or her susceptible to cancer.

"The personal impact of a positive genetic test result is unpredictable," says Joyce Seldon, the registry's genetic counselor. "Many people are unsurprised or relieved to know the facts. A few are devastated. Everyone has had genetic counseling before getting the test results, and there is more counseling after the results are in. It's important to remember that positive results don't mean you'll get cancer. They do mean that lifestyle and medical care changes may be helpful."

People at the registry know of the latest diagnostic, preventive and therapeutic strategies for cancer patients and non-patients at high genetic risk for the disease. Doctors, counselors and psychologists offer preliminary reviews of those alternatives with registry members at no charge.

The registry also offers members the opportunity to help others at risk for cancer.

Every member fills out a detailed, 35-page questionnaire asking for information about everything from "How fast do you usually walk?" to "Have you ever been told by a doctor that you have (any kind of) cancer?"

"The surveys help us serve our members," Ganz says. "And they are a wonderful research tool that can we use in any number of studies. Survey information is analyzed as group data, without personal identification at any point. Anonymity is guaranteed.

"Our registry is about showing people how to give themselves and others like them the best chance at leading healthy, worry-free lives." ★

From left: Dr. Patricia Ganz, Joyce Seldon and a patient

