

The genetic link to breast and ovarian cancer



Genes are found in every cell of the body; they guide our physical growth and development. Genes pass on hereditary information from one family's generation to the next—we all inherit genetic material from our mother and father.

Some families carry certain genes that have been altered or changed over time and do not work as well. In some cases, these changed genes may lead to a higher chance for a person to develop certain diseases, including breast and ovarian cancer. Some of these changed gene types are known as "Breast cancer susceptibility genes," or BRCA. Only two hereditary breast cancer genes have been found through genetic research BRCA-1 and BRCA-2. With more research, new BRCA genes may be identified.

While both men and women may inherit BRCA type genes from their mother or father this does not mean that either will go on to develop breast cancer, or that a woman may also develop ovarian cancer. Breast cancer is less common in men. Also, if you have a family history of breast or ovarian cancer, it doesn't mean that you have altered BRCA genes. In fact, most breast or ovarian cancers that occur within families are not due to inheriting genes. It's believed that less than ten percent of breast cancer is due to alterations in BRCA genes.

Genetic counseling and testing

If you're interested to learn about genetic counseling, talk with your oncologist or personal physician. Your physician will review your family history along with your personal health history to determine if you are at risk. You may be referred to a regional genetic testing center for an informational lecture. Genetic counseling is the first step in determining the chance that a BRCA gene is in your family and if you may have inherited this changed gene. The genetic counselor will review your medical records, your health history and your family history of cancer. The counselor will discuss the risk of your acquiring breast or ovarian cancer and provide you with guidelines for screening and early detection.

Genetic testing is available for individuals who are at very high risk. The decision about taking this blood test is a very personal one and can have complex and sometimes unexpected emotional effects. An important part of genetic counseling is to help you explore what testing might mean for you and your family.

To learn more about genetics counseling and testing, call the Kaiser Permanente Genetics Department location nearest you: Oakland, 510-752-6298; Sacramento, 916-614-4075; San Francisco, 415-833-2998; and Santa Teresa 408-972-3300.

Do I carry the BRCA gene?

If you answer "yes" to one or more of the following indicators, you may have a higher chance of carrying the BRCA gene. Talk with your oncologist or personal physician about any concerns you may have:

- You have a close relative, like a parent or sibling, with a positive test for a changed BRCA gene
- You had both breast and ovarian cancer
- You had breast or ovarian cancer and one or more relatives with breast or ovarian cancer – especially if the breast cancer occurred in a relative before the age of 50
- You had breast cancer before the age of 30
- You have a strong family history of breast or ovarian cancer in many relatives across two or more generations – especially if the breast cancer occurred in a relative before the age of 50
- You are of Ashkenazi (Central or Eastern European) Jewish heritage and have had either breast or ovarian cancer before the age of 50
- You had breast cancer that appeared in both breast or in many places in the same breast

Ann Strange confirms the genetic link...



Above: Ann Strange

"In my mind it was genetic. It was reassuring to have an explanation for what was going on in our family," says Ann Strange, who underwent genetic testing to confirm the hereditary link to this disease.

A breast cancer survivor since 1989, Ann first visited Dr. Howard Kleckner after a mastectomy of her right breast at the young age of 35. She received six months of chemotherapy and hormone therapy to prevent recurrence. Four years later, she developed cancer in her left breast and underwent another mastectomy. Ann lost her mother from breast cancer at age 38, her two sisters also developed breast cancer before age 40.

Recognizing this strong family history, Ann decided to go through the genetic counseling and testing procedure at one of Kaiser Permanente's regional genetic centers. "One reason it was important to do genetic testing is that I have eleven siblings, nine are from the mother who died of breast cancer," says Ann. "My concern was to do anything I could for the next generation."

Her first test, conducted just after genetic testing became available, proved negative. But 12 years later, on the advice of her Kaiser Permanente genetics counselor, Ann consulted with an expert at the University of Washington and tested again. Thanks to improvements in the testing technique, she was found to be a carrier of the BRCA-2 gene. This gene predisposes carriers to an 80 percent lifetime risk of breast cancer and a 30 percent risk of ovarian cancer.

Once a person is confirmed to be a carrier of a BRCA gene, the decision about what to do can be even more difficult. It's especially hard for young women who want to have children. Some carriers are choosing prophylactic mastectomy and

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Meet Glenda Lumpkin, Receptionist



*“Hope is my motto—
it’s the most important thing
we all have.”*

My position in Oncology is one of my most rewarding experiences in life. I’ve come to know so many wonderful and exciting people. Before coming to Kaiser Permanente, I was a buyer for a computer company, a waitress, and mostly a secretary. One day I prayed that I could find a job only working with people. Two weeks later, I landed a position as an on-call receptionist in the Emergency Department. Four years later, I was offered my full-time receptionist position here.

What a blessing. I love my job! Patients are so special to me. Some come in very fearful and some encourage me. Once the ice is broken, many of us become friends. Hope is my motto—it’s the most important thing we all have. Often, I let our patients know that in my 10 years here, I’ve seen many miracles.

Along with my duties, my most favorite is helping people relax and praying for them collectively and individually. I value every single person I meet, including family members and friends. I believe my encounters with patients are meant to be. I’m thankful for my co-workers and their patience with me during my ‘senior moments’—I consider them my extended family.

For those of you who don’t know, I’ve been married to my husband Doug, a Hayward/Fremont Emergency Department Nurse for nine years. We have two children and two grandchildren.

Physical Therapy Team specializes in Lymphedema care

by Ann Gordon, MPH



Not only do cancer patients have to cope with recuperating from surgery, chemotherapy and radiation, but often there are lasting effects of surgery that require lifetime maintenance. One effect is lymphedema, a swelling that occurs in the limbs after lymph nodes are removed from the body. Our local Kaiser Permanente team of physical therapy specialists treat and help members prevent this little known condition.

What is lymphedema?

Lymphedema is a build up of lymphatic fluid that can cause swelling. When lymph nodes are removed from the body, scar tissue can develop in their place. Scar tissue impedes the flow of lymph fluid and causes swelling. Radiation treatment can also trigger or aggravate lymphedema. Our lymph system removes impurities from the body’s tissue and produces cells that are vital to fighting infections. We have hundreds of lymph nodes in our bodies, so the removal of a few does not damage the lymph system.

In some cases, lymphedema can be prevented by taking precautions such as avoiding injections, blood draws and in the affected arm, and by protecting the arm from infection, and by avoiding the sun and heavy lifting.

Helping patients find relief and learning how to cope with lymphedema is a specialty of Linda Joost, Anneli Keller, and Diane Rodriguez, Physical Therapists at our Union City Medical Offices. The team offers a comprehensive lymphedema education program and personalized physical

therapy appointments for patients.

“The thing patients appreciate about the lymphedema class is getting the information before it happens,” says Linda Joost, Physical Therapist. “It’s better to be educated about lymphedema so you can prevent it from happening or get immediate treatment before it’s severe. Usually, four to seven members participate in each one and one-half hour class and they can bring their family members. We go over precautions and the anatomy of the lymph system, check the patients’ range of motion in the affected limb, and provide treatment for those in need. We also teach self-massage, and how to improve diet and exercise for a healthier lifestyle.”

Anneli Keller, Physical Therapist, bubbles with enthusiasm about the program, “It’s great that we’re catching all these patients early so we can intervene early. By telling them the signs of lymphedema, if they do get it, it’s not as scary,” says Anneli.

“The program, and my visits with Anneli Keller, helped put the lymphedema precautions into perspective,” says breast cancer survivor, Sherry Klepper. “It’s helped me figure out how to incorporate the precautions without being overwhelmed or feeling like I had to think about my lymphedema all the time.”

Diane Rodriguez, who delivers the program along with Linda and Anneli, says, “Patients love that they come over quickly for the class because they’ve heard about lymphedema from friends and acquaintances. They feel taken care of by Kaiser when they get referred to the program.”

Physical Therapy Team: *Con’t page 4*



Left to Right: Physical Therapy team members Anneli Keller, Diane Rodriguez, and Linda Joost.

If my cancer comes back

by Debbie Moore, RN, Nurse Practitioner



In the back of every cancer

patient's mind is the possibility that the disease may return. And if it does, there is the same anger, fear, and the unanswered question, 'will the treatment work this time?' But there is a difference if you've been through this before and you know the medical care and emotional support are available to you and your family.

A cancer recurrence is the reappearance of disease that was believed to be cured or inactive (remission). Cancer can recur after several months or many years later. It's not a new cancer; it has the same appearance in cell type as the original tumor even if it is found in a new place. Recurrence happens because some of the original cancer cells were not removed or destroyed by previous treatments. In other words, a small number of cells survived and began to grow into tumors which are now big enough to be detected. The spread of cancer cells to a new part of the body is called *metastases*.

Cancers can be recurrent locally—they grow very close to the region of the original tumor. When someone experiences a regional recurrence, it usually involves a tumor in lymph nodes or tissues near the original site of the cancer but with no evidence of what is called, distant spread. In distant spread, the original cancer has metastasized or spread to organs or tissues in other parts of the body.

Diagnosing recurrent cancer involves careful follow-up. Always report specific symptoms and changes in your body to your physician. While these symptoms don't always mean cancer, you should report any weight change, bleeding, pain, shortness of breath, or a cough that doesn't go away. Your physician may find signs of illness during a physical examination. Specific procedures and tests will be used to determine the exact cause of a problem and help you and your physician decide on the best treatment.

Much of the fear and anxiety you felt the first time was 'fear of the unknown.' You can help yourself again by gathering information, by being as active in your

treatment as possible, and by finding the emotional support you need. Your family also may need help in working through a sense of helplessness. Learn as much as you can about what is happening to you—ask your physician, nurse, pharmacist, and other members of your health care team.

Patients experience many overwhelming emotions when cancer recurs. Your sense of well-being is threatened. Cancer treatments not only place demands on your body but on your spirit. You'll experience good days and bad days. Some days you may simply want to cry and that's okay.

On a bad day, try to remember that there have been good days. Feeling low today doesn't mean you'll feel this way tomorrow. Reading a book, planning a new garden, or calling a friend, may help. Sharing your feelings with others, especially family, can better help all of you through a difficult time. Another booklet, *Taking Time*, offers useful advice for patients and families.

Our Kaiser Permanente social workers, counselors, and local support groups offer helpful forums for expressing your thoughts and feelings. For more information, please refer to the *Lifelines* section of this newsletter or just ask one of us in Oncology.

Patient Tips for Support

- Take an active role in your treatment
- Eat well and maintain your nutrition*
- Get extra rest and adjust your activities
- Write down your questions
- Ask family or a friend to come with you to appointments
- Speak openly about your needs so you receive the most useful advice

*The National Cancer Institute's booklet, *Eating Hints for Cancer Patients*, is available by calling 1-800-4CANCER

Ann Strange confirms the genetic link...: *Con't from page 1*

reconstruction and oophorectomy to reduce their risk. Other women are choosing watchful waiting. Since Ann had her children and had experienced two mastectomies, she decided to undergo a prophylactic hysterectomy and ovarian removal.

"Now, several more people in my family have been tested," says Ann. "Two of my brothers tested positive and my sister, who's experienced breast cancer, is presumed positive. It's hardest for my nieces—the daughters of one of my positive brothers—because they also have tested positive."

Ann's two young nieces face grave decisions; neither have married or started a family. One has chosen to undergo bilateral mastectomies with reconstruction at age 28. The other continues to grapple with her decision. Both young women would like to have families. Ann's other siblings are considering genetic testing; and many of their

"My concern was to do anything I could for the next generation."

—Anne Strange

children are still too young to be tested. Ann's 19-year-old daughter has decided not to get tested at this time.

"I see myself as the person to get the information out to the family so they can make informed decisions," says Ann. "It's hardest for the guys because they're not sure of what to be aware about. Men with the gene can have increased risk of melanoma, prostate and colon cancers. They need to get regular screening."

"I would like to compliment Kaiser Permanente for including testing as part of our health care coverage," says Ann. "It made it so much easier to

get tested because there was a place to go with trained counselors and the fee was covered. I meet many women outside of Kaiser who are considering getting tested, but never go through with it because it's too difficult and expensive."

Ann encourages women who are still considering getting tested. "Even if you don't want to go through with it, it's valuable to be counseled because you'll get advice on why testing might be helpful that you haven't considered," she says.

She also recommends the online support group *Facing our Risk of Cancer Empowered* at www.facingourrisk.org. "There are people who have tested positive and who are considering testing because they have a strong incidence in their family," says Ann. "It's a great source of information and encouragement, and there are many long-term survivors on the site which give me hope and comfort."

Outlook—tributes and transitions

by Howard Kleckner, MD



This edition of Outlook marks our first anniversary of publication. We thank the many friends, members, physicians, and department staff who so generously contributed to all four editions.

We especially extend warm thoughts to the families and friends of those patients we lost during the year. So many who touched our lives with such grace. Among them contributing in *Outlook*, Mable Artley, Chuck Breeden and Andrew Munoz, Sr.—their stories of courage, hope, and independent spirit continue to serve as an inspiration to all of us.

Clinical Trials Program Expansion

by Kathy Walker, RN, clinical research nurse

The Kaiser Permanente

Oncology Clinical Trials Program continues to grow. With new trials opening recently, we now offer more than 30 trials as a treatment option for members in Northern California. We currently offer trials for breast, lung, colon, prostate, ovarian, pancreatic, lymphoma, melanoma, a type of leukemia known as CLL, and studies for other less common cancers.

Each trial study has specific 'eligibility criteria' that must be met before a person can enroll. Researchers seek answers to questions about treatment for a specific type of cancer at a specific stage of its development, from early stages through the more advanced. By enrolling only those persons who meet the eligibility criteria the group is comprised of people with similar characteristics for a specific type of cancer. This



criteria helps strengthen the results of the research study.

Am I eligible?

Your Oncology Department physician and research staff will review your medical history and test results related to your cancer diagnosis. If it appears that you may meet the eligibility criteria for a specific study, and may benefit from receiving treatment through a trial, your physician will present a trial as one possible treatment option.

As always, participation in a clinical trial study is voluntary. Being eligible to participate provides you and your physician with more choices as you decide together how best to treat your cancer.

For more information, please stop by my office in the Oncology Department, or call me at 510-784-4533.

Physical Therapy Team: *Con't from page 2*

Sherry offers advice to other cancer survivors. "If a person has any slight swelling or redness in their affected limb, see your oncologist for a referral. Dr. Kleckner was quick to act when I had problems with my arm. This made a big difference because addressing slight swelling is easier than if your arm gets big."

"I also recommend the National Lymphedema Network as a resource for people wanting to learn more," says Sherry. "They have an 18-step prevention statement and lots of lymphedema resources which can be hard to find. This is where I found out about the lymphedema support group that I attend."

For more information on the Kaiser Permanente Lymphedema Education Program, call Ann Gordon, at 510-784-6767.

Lymphedema Resources:

- National Lymphedema Network
800-541-3259 or www.lymphnet.org
- Lymphedema Support Group
Mt. Diablo Medical Center
2nd Saturdays Monthly, 10:00 am
925-674-2125

Welcome



Dr. Grant Goodman joined our Oncology Department team in July. A native of Cape Town, South Africa, Dr. Goodman specializes in Hematology and Oncology. He received his medical degree from the University of Cape Town and completed residency at the Albert Einstein Medical Center. A recent fellow in Hematology and Oncology at Scripps Clinic and Research Foundation in San Diego, Dr. Goodman is board certified in Internal Medicine.

LifeLines

LOCAL CANCER CLASSES & SUPPORT GROUPS

Cancer Support Groups call for more information, we have numerous groups available

Prostate Cancer Support Group a monthly support group for patients & family members

I Can Cope a 7-session class for newly diagnosed patients and their families

Chemotherapy Overview a one-session class on side effect management for patients undergoing chemotherapy is held every Tuesday

Look Good, Feel Better a one-session class on self-care and beauty tips for women undergoing chemotherapy is held every other month on Mondays

Breast Cancer Support Group is held every other Wednesday

Mind Body Medicine Program 8-session workshop for those interested in improving their health & managing stress

Kaiser Permanente Health Education:
Hayward and Union City: 510-784-4531
Fremont: 510-248-3455

WEB SITE RESOURCES:

www.kaiserpermanente.org <http://fremont.kp.org>
www.permanente.net/doctor www.cancer.gov
<http://hayward.kp.org> www.cancer.org

Note: Web site links are provided as an educational tool. Any medical content that you feel may be important to your health should always be discussed with your Kaiser Permanente physician.

OUTLOOK EDITORIAL STAFF

Editorial Director: Howard Kleckner, MD
Contributors: Nancy Dyal, Ann Gordon, MPH, Howard Kleckner, MD, Glenda Lumpkin, Debbie Moore, RNP, Kathy Walker, RN members and friends

We want to hear from you! Comments, ideas, stories – contact us at the Oncology Department, Kaiser Permanente Hayward Medical Center, 27400 Hesperian Blvd, Hayward CA 94545 or send and email to: Howard.Kleckner@kp.org.