



Your guide to the Hereditary Cancer Risk Center

Providing support and knowledge to help you
choose your personal treatment plan

Welcome

Learning that you've inherited a high risk of cancer may bring on a rush of emotions for you and your family.

The news might make you feel as if your whole world is changing. Or you may feel empowered – now that something you've suspected has been confirmed, you can take control of your health.

Your Kaiser Permanente care team understands these feelings and is committed to helping you through this journey. This booklet will help you understand what to expect from your first appointment, and the types of discussions you'll have with your doctors. These conversations will help you make informed decisions about the most appropriate care plan for you.

When it comes to managing cancer risk, one size doesn't fit all. Your lifestyle and your personal preferences will affect your care choices. We're here to help you work through these complex decisions so you feel comfortable with your treatment plan and ready to engage with your health.



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The Hereditary Cancer Risk Center


The center is designed for women who have a high risk for breast, ovarian, and uterine cancer – both those who’ve had a cancer diagnosis and those who haven’t – and for those seeking follow-up care. You’ll get coordinated care and save time by seeing many specialists during the same visit.

You and your family will work with our multidisciplinary team of care providers to personalize your cancer screening schedule and discuss your treatment options. These specialists concentrate on caring for people who face an inherited risk. They can provide valuable information about strategies that could help you reduce your risk or prevent cancer.


There are 6 hereditary cancer risk centers in Northern California, located in Fresno, Oakland, Sacramento, San Francisco, San Jose, and Vallejo. You’re welcome to go to the center most convenient to you.

What can I expect at my appointment?

Before you arrive, your specialists will meet to review your medical records, get input from your genetic counselor, and discuss your situation.

 **When you arrive**
When you get to the center, you'll check in with our friendly staff and go over the plan for your visit.




 **Meeting with your care team**
Based on your needs and preferences, you'll meet individually with members of your care team to discuss cancer prevention and risk-reducing strategies. You might be meeting with:



A gynecologist who may perform a pelvic exam and will discuss cancer screenings and risk-reducing options, which may include surgery.	A breast surgeon who will perform a breast exam and discuss cancer screenings and risk-reducing options, which may include surgery.	A plastic surgeon who may also perform a breast exam and discuss reconstruction options, if you're considering a mastectomy.
A genetic counselor who will review your risk of cancer, and explain how this risk can affect your family.	Other providers who may include a nurse practitioner or medical oncologist.	

All of these providers have special knowledge and experience to help you make informed decisions about your individual care.



 **At the end of your visit**
Your team will go over your customized cancer risk management plan, based on your conversations during the appointment. You won't have to decide about treatment that day, but you should have the information you'll need to begin thinking through your choices.

Depending on how many specialists you're scheduled to see, your appointments may last up to 2 hours in total.

How do I prepare for my first appointment?

When you schedule your appointment, your center coordinator will discuss any necessary preparations. You may be asked to get a baseline screening, which can include a breast MRI, a mammogram, a pelvic ultrasound, and a blood draw for CA-125. In some cases, these screenings will take place after your visit.

Here are a few other things you can do:

- Write down any questions you may have in the back of this booklet and bring it with you to the appointment. You'll receive additional information to take home.
- Ask a support person to come with you to your clinic visit.
- Arrive 15 to 20 minutes early to allow time for parking and registration.

“ Learning about my increased risk for cancer was difficult because it meant having to face my greatest fears. With Kaiser Permanente’s expertise and guidance, I felt empowered to take an active role in my health. Making decisions about how to deal with my harmful genetic mutation became easier once I had the commitment and support of my health care team.”

– **Kristi B.**, BRCA carrier and “previvor”
(survivor of an inherited risk for cancer)

What will the team recommend to help reduce my cancer risk?

While your care plan will be personalized for you, it's helpful to know some common recommendations from the hereditary cancer risk center.

At your first visit, you won't need to make any decisions about acting on these recommendations. There's a lot of information to absorb, so you may want to take time to consider your options before making a decision.

Typical recommendations include:



Screenings

- Breast cancer screening: mammogram and breast MRI
- Ovarian cancer screening: pelvic ultrasound and blood test
- Endometrial cancer screening: uterine biopsy



Lifestyle:

- Exercise: 150 minutes per week (30 minutes, 5 times per week)
- Bone health: make sure to get enough calcium and vitamin D
- Alcohol use: no more than one drink per day
- Diet: high in vegetables and fruits, low in fats and sugars
- Weight: maintain a healthy weight
- Menopausal symptoms: how to manage hot flashes and changes in libido and sexuality



Medications (when appropriate)

- Tamoxifen may reduce the risk of breast cancer
- Oral contraception pills may reduce the risk of ovarian cancer
- IUD use may reduce the risk of uterine cancer



Surgery (when appropriate)

- Breast cancer: mastectomy with or without reconstruction
- Ovarian cancer: removal of the ovaries and fallopian tubes (salpingo-oophorectomy)
- Uterine cancer: removal of the uterus (hysterectomy)



What can I expect after my appointment?

At the end of your visit, your team will review your customized cancer risk management plan, based on your conversations during the appointment.

Your care plan will include:

- A personalized schedule for cancer screening
- Risk-reduction recommendations based on your needs and preferences
- Educational resources to take home
- Future appointment plans

Your personal doctor will also receive a summary of these recommendations.

If you wish, we can also refer you to a wellness coach, nutritionist, social worker, or financial consultant.

We want to help you get the support you need. Please see the list of additional Kaiser Permanente resources on p. 9, and community support services on p. 10.



Can I have a video consultation instead of meeting in person?

You may find it valuable to meet with your care team in person. A physical exam might be necessary.

But if you're already getting care at another facility, or if you live far from the center, a video consultation might be useful.

If you're interested in a video visit, please ask your center coordinator. The coordinator can help you decide what kind of consultation may best meet your needs.

“After I tested positive for a BRCA1 mutation, I was initially in denial and feeling scared about the future. Scheduling my first visit with the cancer risk clinic helped me feel more proactive about taking control of my health.”

– **Carol J.**, BRCA carrier and “previvor”
(survivor of an inherited risk for cancer)



What support services does Kaiser Permanente provide?*

You have access to a variety of resources that are available online and in person. The center coordinator or other members of your care team can help connect you with services, including:



In-person classes

Learn about mindful meditation and relaxation, yoga, stress management, sleep solutions, and other practices



Nutrition counseling and classes

Take advantage of the power of food to help improve your health and boost your energy



Wellness Coaching by Phone

We'll partner with you through convenient phone sessions to create a customized plan to help reduce stress, eat healthier, manage your weight, quit tobacco, or increase activity



Online programs

Get the advice, encouragement, and tools to help you make healthy changes



Support groups

Connect with emotional support and useful information for people managing cancer

To learn more about these programs and classes, visit kp.org/classes.

*Some classes may require a fee.

What other resources are available in my community?*

Facing Our Risk of Cancer Empowered (FORCE)

facingourrisk.org

Provides support, education, and awareness to help those facing hereditary breast, ovarian, uterine, and related cancers. Has a free Peer Navigation Program that connects you with someone who shares a similar journey.

Bright Pink

brightpink.org

A national nonprofit organization focused on prevention and early detection of breast and ovarian cancer in young women. Their PinkPal program matches young women at increased risk for cancer with fellow at-risk individuals.

Bay Area Cancer Connections

bcconnections.org

Offers one-on-one support, social activities, and a variety of support groups for people affected by breast or ovarian cancer. The Buddy Program connects cancer survivors with someone who's had a similar diagnosis or treatment experience.

BRCA Umbrella

brcaumbrella.ning.com

Social network for those at high risk for breast and ovarian cancer. Provides forums, blogs, and resources with free registration.

*Kaiser Permanente does not endorse the organizations mentioned. Any trade names listed are for easy identification only.

Are there opportunities to volunteer or participate in clinical research studies?

Research and clinical trials

When you volunteer for a research study, you may help deliver the many benefits of health research: discovering the causes of disease, developing new treatments, and improving the quality of medical care.

The Kaiser Permanente hereditary cancer risk centers are actively involved in research and clinical trials related to gynecologic and breast cancer. Many of the research studies include women who are at inherited risk for cancer.

A sample of recent trials or those in development includes:

- A pilot study of multiple biomarkers with the risk of ovarian cancer algorithm (ROCA) for early detection of ovarian cancer in female carriers of BRCA1 and BRCA2
- Incidence of osteoporosis and abnormal lipid profiles and other health outcomes in women over age 40 who test positive for a BRCA1 or BRCA2 mutation and have had a risk-reducing salpingo-oophorectomy

If you're interested in learning more about research studies, let one of your care team members know. Ask what's available within Kaiser Permanente. There are clinical trials for women with cancer as well as for cancer survivors. You can also search [ClinicalTrials.gov](https://clinicaltrials.gov) to find trials for which you may be eligible.

Share your insights

We value your input. Would you like to help us improve the care experience for people with a hereditary risk for uterine, breast, and ovarian cancer? We're looking for members to help ensure that our educational materials, support resources, appointment processes, and communications meet the needs of patients and their families.

Contact your center coordinator if you're interested in learning more.

Notes

A series of horizontal dotted lines for taking notes.

