Hereditary Cancer in the Jewish Community

Getting Screened: Hereditary Cancer Syndromes

NORTON & ELAINE SARNOFF CENTER FOR JEWISH GENETICS

Jewish United Fund TOGETHER *for* GOOD

Hereditary Cancer: The Basics

Everyone faces a risk of cancer; however, some individuals may be at a higher risk based on their family history and/or ethnic background.

KNOWN RISK FACTORS INCLUDE:

- Ashkenazi Jewish ancestry
- Cancer diagnosed before age 50
- Multiple types of cancer in the same person
- Cancer found in both organs that come as a pair
- Several close relatives on one side of the family with the same or related cancers, examples:
  - Breast (female or male), ovarian, pancreatic, prostate
  - Colon, uterus, ovarian, stomach, kidney, brain
  - Melanoma and pancreatic cancer
- Multiple generations in the family affected with cancer
- Rare cancers such as ovarian cancer, male breast cancer, paragangliomas, medullary thyroid cancer

WHAT CONDITIONS ARE MORE COMMON AMONG ASHKENAZI JEWS?

There are several hereditary cancer syndromes that occur more frequently in people of Ashkenazi Jewish descent including:

APC I1307K Risk Allele
This variant is found in 6% of the Jewish population and causes a 2–3-fold increase of developing colon cancer.

Hereditary Breast and Ovarian Cancer Syndrome (BRCA1/2)
Mutations in these genes are found in 1 in 40 Jews and increase the risk of breast, ovarian, pancreatic and prostate cancer.

Hereditary Mixed Polyposis Syndrome (GREM1)
A variant in this gene is found in ~1% of the Jewish population and causes a high chance of developing multiple colon polyps and colon cancer.

Lynch Syndrome (EPCAM, MLH1, MSH2, MSH6, PMS2)
This condition is found in ~1% of the Jewish population and increases the risk of several cancers including colon and uterine cancer.

Not sure where to begin? The Norton & Elaine Sarnoff Center for Jewish Genetics can help you get started.

Genetic counseling services can help you further assess your risk and decide whether or not to get genetic testing. Genetic testing technology changes rapidly. If you received testing in the past, a genetic counselor can help you determine if additional testing is appropriate for you or your family.

Screenings: Who, What, When & Where

WHO SHOULD BE SCREENED?

- All individuals of Ashkenazi Jewish ancestry can consider testing
- Individuals with any known risk factors

WHAT DOES SCREENING INVOLVE?

The tests are typically completed with a saliva sample, but a blood sample may be used. Laboratories use different methods for testing. The most advanced form includes full gene sequencing as this provides the highest detection rates. Hereditary cancer testing includes the most common occurring cancers and depending on the level of testing ordered, may include rarer cancer types. Your healthcare provider determines which tests to order, so it's important to let your healthcare provider know about your personal and/or family history of cancer and Ashkenazi Jewish background.

WHEN SHOULD I GET SCREENED?

Testing is typically done in adulthood after consultation with a healthcare provider to assess your risk factors. Understanding your cancer risk early helps guide when to begin screening, which screenings you need and what steps you can take to lower your risk. If you have had cancer, genetic testing may help with treatment recommendations (both surgeries and therapies) in addition to how to move forward with future cancer screening.

You may wish to know this information before family planning if you have concerns about passing a hereditary cancer risk to future children. There are assisted reproductive technologies available that can reduce the chance of passing on a hereditary cancer risk to future children.

WHERE AND HOW DO I GET SCREENED?

Talk to your primary care provider about genetic screening. Your healthcare provider and/or OB/GYN may order the test for you.

The Norton & Elaine Sarnoff Center for Jewish Genetics offers affordable and accessible screening for all eligible participants. The Sarnoff Center will also help you locate a local resource if you live outside of Illinois.

Results: What If I Test Positive?

HOW DO I MANAGE A POSITIVE TEST RESULT?

A positive genetic test result means that you have been identified to have a hereditary risk of cancer; this means that your chance of developing cancer is higher than average. Based on the gene and cancers associated with that gene, you will be offered a set of cancer screening recommendations that typically include earlier and more frequent cancer screenings. For some cancers, risk reducing options such as surgery or medications will be discussed as well.

WHAT DOES THIS MEAN FOR MY FAMILY?

All of your biological family members may also have the same hereditary cancer risk and the chance that they would have it depends on how closely related they are to you. For example, most of the genes are passed down in an 'autosomal dominant' manner, meaning you need only 1 copy of the gene to not be working (mutated) to have the increased cancer risk.

For dominant conditions...

You have a

chance of passing the hereditary risk to children

Your parents and siblings would have a

chance of having the hereditary risk as well

Some genes cause a hereditary cancer risk in an 'autosomal recessive' manner, meaning **both** copies of the gene have to be mutated to have the hereditary cancer risk. With recessive conditions, one mutated gene rarely increases the risk of cancer. The chance that your children could have the same condition would depend on the genetics of the other biological parent.

Your siblings would have a

chance of having the same condition

Both of your parents would at least be 'carriers' and have one non-working copy of the gene

Affordable, Accessible Hereditary Cancer Testing in Illinois

The Norton & Elaine Sarnoff Center for Jewish Genetics provides an accessible screening option for Jewish individuals and families. The Sarnoff Center's program allows most participants to get screened right from home... **in 6 simple steps!**

01. Visit **www.jewishgenetics.org** and register for the program
02. Complete an online education course to prepare for screening
03. Our genetic counseling partner will contact you after completion of the course
04. After receiving a saliva kit in the mail, return a saliva sample using the instructions in the kit
05. Our genetic counseling partner will call you with results 2–3 weeks after the kit is sent in for testing
06. Follow-up appointments will be scheduled as needed with our genetic counseling partner

There is a program fee of $99, which includes pre-screening education and support through the Sarnoff Center and our healthcare provider. In most cases, the healthcare provider will bill your insurance for the cost of the test. You may request financial assistance from the Sarnoff Center for the program fee and/or genetic test. One of the goals of the Norton & Elaine Sarnoff Center for Jewish Genetics is to ensure that no Jewish individuals and families go without genetic screening due to concerns about cost or ability to pay.

You Could Be at Risk Even If...

You are "a little bit Jewish"
Just one Jewish parent, grandparent or great-grandparent is enough to increase the chance an individual has a hereditary cancer risk.

You are not a practicing Jew
Your level of faith does not impact the genes you were born with so if you have a Jewish parent, grandparent or great-grandparent, genetic testing may still be warranted.

You have no family history of cancer
Genes linked to sex-specific cancers (such as ovarian cancer) can be inherited from a parent of the opposite sex without causing symptoms. Additionally, carrying a hereditary cancer risk does not guarantee that cancer will develop. Recessive disorders can only appear when both parents carry the same disease, but the mutation may pass down for generations without producing an affected individual.

You had a negative genetic test years ago
Genetic testing technology has improved dramatically. In addition, the number of genes that we test for has increased over the years. If you were tested before 2015, additional genetic testing is likely warranted. If you were tested between 2015 and 2019, contact the Sarnoff Center to see if additional testing is recommended.

A family member had a negative genetic test
For the same reasons mentioned above, it may be worth considering additional testing. Plus, genetic testing for you would assess both sides of the family whereas testing a single relative may only assess the risk from one side of the family.

NORTON & ELAINE SARNOFF CENTER FOR JEWISH GENETICS

The Norton & Elaine Sarnoff Center for Jewish Genetics provides educational resources related to hereditary cancers and genetic disorders more common among individuals of Jewish descent. We work closely with community members, clergy, healthcare professionals and partner organizations to raise awareness of these issues and available support options, including our own low-to-no-cost genetic counseling and genetic screening programs.

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This information is to be used for educational and informational purposes only. This information does not represent advice regarding medical diagnosis or treatment, referrals to healthcare providers, endorsements of healthcare products or any other recommendations. This information should not be relied upon as a substitute for consultation with your healthcare providers.

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