# **RESULTS:** WHAT IF I'M A CARRIER?

#### DO I NEED TREATMENT?

For the majority of genetic diseases on carrier screening panels, carriers do not develop the disorder and treatment isn't needed. However, carriers can pass the disorder to their children.

For some recessive conditions, carriers may have mild symptoms or other associated health risks. In rare instances, genetic screening may reveal a person has a less severe or late-onset form of a genetic disorder. In these cases, your doctor can provide recommendations for management and follow up options.

# CAN I PASS THESE DISORDERS ON TO MY CHILD?

Most Jewish genetic disorders are inherited in an autosomal recessive pattern, which means both you and your partner must be carriers of the same condition in order to have an affected child.

If you and your partner carry the same disorder, with each pregnancy, your child will have a...



chance of being **AFFECTED** 



chance of being a **CARRIER** 



chance of being **NEITHER**affected/carrier

## **CAN I STILL HAVE HEALTHY CHILDREN?**

Yes! Carrier couples build healthy families every day. Based on your carrier status and when you are tested, you'll have many options for planning a healthy family.

# INTERFAITH FAMILIES AND HEREDITARY CANCERS

Individuals of Ashkenazi Jewish descent are 10 times more likely to have a mutation in their *BRCA1* or *BRCA2* genes than the general population. BRCA mutations increase the risk of breast cancer, male breast cancer, ovarian cancer, prostate cancer, and pancreatic cancer.

BRCA mutations are found in both men and women and can be passed down to sons or daughters. Unlike recessive conditions that fall under the umbrella term "Jewish genetic disorders," BRCA mutations are inherited in an autosomal dominant fashion. Individuals with a BRCA mutation have a 50% chance with each pregnancy that the child will inherit the gene mutation and a 50% chance the child will not inherit the mutation.

BRCA mutations, as well as mutations in other hereditary cancer genes, can occur in both Jewish and non-Jewish individuals. If you have concerns about your inherited cancer risk, meet with a genetic counselor or physician to discuss your personal and family history of breast, ovarian, and other cancers.

Not sure where to start? Contact the Norton & Elaine Sarnoff Center for Jewish Genetics for more information or to speak to a genetic counselor, who can provide education, answer questions, and direct you to appropriate clinical resources.





# An INTERFAITH GUIDE

# to Jewish Genetics



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The Norton & Elaine Sarnoff Center for Jewish Genetics is a supporting foundation of Jewish United Fund of Metropolitan Chicago, and is supported in part by the Michael Reese Health Trust.

## RESOURCES

The Center has a variety of resources to help you find everything you need – including local screening information, support organizations, and research.

Learn more at **jewishgenetics.org**.

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# **JEWISH GENETIC DISORDERS:**

THE BASICS

# CARRIER SCREENING FOR INTERFAITH COUPLES

If you or your partner is of Jewish descent (at least one Jewish parent, grandparent or great-grandparent), you may be at higher risk for having a child with a genetic disorder. For years, health professionals have urged Jewish couples to get screened for genetic disorders more common in the Jewish community. But the truth is, interfaith couples where only one partner is of Jewish descent should also be screened for Jewish genetic disorders and should consider expanded carrier screening.

Jewish genetic disorders are a group of recessive disorders that occur more frequently among individuals of Jewish descent, with potentially serious or life-threatening consequences for affected children.

 An individual's risk is based on genetic ancestry, not on religious practices or observances. Having just one Jewish grandparent or great-grandparent is enough to increase a person's risk, regardless of religious beliefs or cultural affiliation.

Genetic screening plays an important role when you're starting your family.

The Norton & Elaine Sarnoff Center for Jewish Genetics can help you understand your risk and options.

# **SCREENINGS:** WHO, WHAT, WHEN & WHERE

## WHO SHOULD BE SCREENED?

Sephardic Jews may consider expanded genetic screening

Non-Jewish partners, as none of these

All persons with Ashkenazi Jewish ancestry

Non-Jewish partners, as none of these disorders are exclusive to the Jewish population

## WHAT DOES SCREENING INVOLVE?

Laboratories use different methods for screening.
The most advanced form, Next Generation
Sequencing (NGS), provides the highest detection
rates. NGS panels typically include most or all of the
Jewish genetic disorders. In addition, many NGS
panels screen for an expanded number of conditions,
including pan-ethnic conditions that are found
equally across all ethnicities.

While carrier screening has traditionally been based on ethnicity, an increasing number of individuals are of mixed or unknown ancestry. Additionally, while some mutations are particularly common among people who share the same ethnic background, anyone can be a carrier of any genetic disorder. Expanded carrier screening panels can help identify a couple's risk of passing on certain inherited disorders, regardless of ethnicity.

Most NGS tests can be accomplished with a saliva sample, but others require a blood sample.

Cost can vary depending on your insurance coverage. Some community-based screening programs offer subsidized screening services.

### WHEN SHOULD I GET SCREENED?

Screening is always recommended prior to pregnancy. Knowing your carrier status beforehand gives you the most options when planning for a family.

If you or your partner is already pregnant, you should seek screening right away. If you're both carriers for the same recessive condition, it is possible to do additional testing during pregnancy. Early fetal testing can give you more time for counseling and decision-making.

### WHERE & HOW DO I GET SCREENED?

There are several ways to get screened. You can seek screening through your doctor, through a specialized provider such as a genetic counselor, or through a community-based program. If you seek screening through your physician or a specialized provider, it's important to let them know your ethnicity so they can order the most appropriate test.

For Jewish and interfaith couples in Illinois, the Norton & Elaine Sarnoff Center for Jewish Genetics is a community-based program that provides access to screening. The Sarnoff Center can help you locate a local resource if you live elsewhere.



Absolutely get tested - so that you can know. Whatever choice you want to make, at least know the cards you're dealt. I believe that knowledge is power and without knowledge we could not have made the choices that were best for us."

A Canavan carrier couple and parents of a healthy girl

# AFFORDABLE, ACCESSIBLE GENETIC SCREENING IN ILLINOIS

The Sarnoff Center's online program allows most participants to get screened right from home... in 5 simple steps!



Visit jewishgenetics.org and register for the program



Complete an online education course



Register for the screening test and receive a saliva collection kit



Mail your saliva sample to the medical provider



Receive your results from a genetic counselor in 3 weeks

A program fee includes pre-screening education and support through the Sarnoff Center and a medical provider. The Sarnoff Center offers a payment assistance program to help with testing and counseling costs not covered by insurance.

The Sarnoff Center's screening program uses an expanded panel that screens for conditions found in the Jewish and general populations, making it a comprehensive test for Jewish and interfaith couples. Females who participate in the Sarnoff Center's program also are screened for several X-linked conditions, which are typically passed down from carrier mothers to male children. For this reason, the female partner should get screened first – regardless of ethnicity - in cases when partners decide not to be tested at the same time.

To get started or for more information, please visit jewishgenetics.org or contact the Norton & Elaine Sarnoff Center for Jewish Genetics at (312) 357-4718 or jewishgenetics@juf.org.