

JEWISH GENETIC DISORDERS: THE BASICS

- 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.
- At least 50 genetic disorders are more common among **Ashkenazi** (Central or Eastern European) Jews, with potentially serious or life-threatening consequences for affected children. In fact, at least 1 in 4 Ashkenazi Jews carries one or more of these conditions.
- Persons of **Sephardic** (Mediterranean or Middle Eastern) Jewish descent may also experience higher risk depending on their ancestral country of origin.
- 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?

- All persons of Ashkenazi Jewish descent
- Sephardic Jews and their partners may consider expanded genetic screening
- 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 include most or all of the Jewish genetic disorders. Your doctor determines which tests to order, so it's important to let your doctor know your heritage.

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 your family.

If you or your partner is already pregnant, you should seek screening right away. If you're both carriers for the same condition, early fetal testing can give you more time for counseling and decision-making.



WHERE & HOW DO I GET SCREENED?

Your doctor may either order the test or refer you to a specialized provider for genetic counseling and testing services. Alternatively, you may have the option of making an appointment directly with the specialized provider.

Community-based programs also provide access to screening. In Illinois, the Norton & Elaine Sarnoff Center for Jewish Genetics is one such program. The Sarnoff Center also has the ability to help 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

RESULTS: WHAT IF I'M A CARRIER?

DO I NEED TREATMENT?

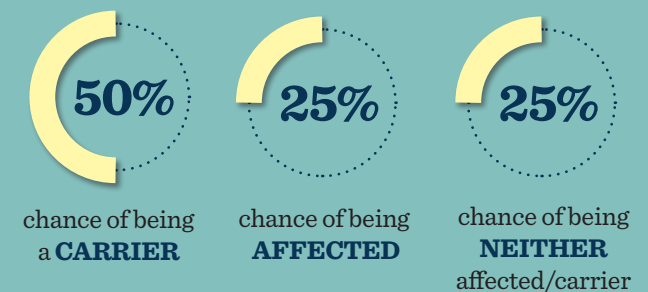
Carriers do not develop the disease, so treatment isn't needed. However, carriers can pass the disease to their children.

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 the appropriate options.

CAN THE DISORDER PASS TO MY CHILD?

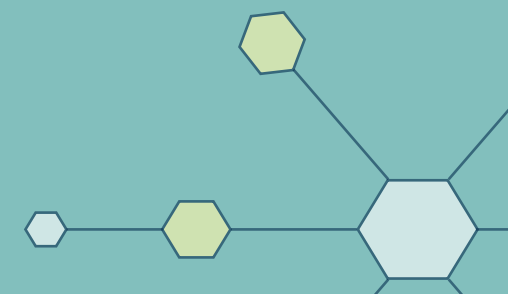
Jewish genetic diseases are “autosomal recessive,” meaning both you and your partner must carry the same mutated gene to have an affected child.

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



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. Visit the Norton & Elaine Sarnoff Center for Jewish Genetics website for additional information.



AFFORDABLE, ACCESSIBLE GENETIC SCREENING IN ILLINOIS

The Norton & Elaine Sarnoff Center for Jewish Genetics provides an accessible screening option for Jewish and interfaith couples. The Center's online program allows most participants to get screened right from home... in 5 simple steps!

- 01.** Visit jewishgenetics.org and register for the program
- 02.** Complete our online education program
- 03.** Register for the screening test and receive a saliva collection kit
- 04.** Mail your saliva sample to the medical provider
- 05.** Receive your results in 3 weeks

The program fee includes pre-screening education and support through the Sarnoff Center and a medical provider. In most cases, the medical provider will bill your insurance for the cost of the test and related genetic counseling. Before or after testing, you may request payment assistance from the Sarnoff Center to cover any remaining balance after insurance.

For more information, visit our website at jewishgenetics.org

YOU COULD BE AT RISK EVEN IF...

YOU OR YOUR PARTNER IS ONLY "A LITTLE BIT JEWISH"

Just one Jewish parent, grandparent, or great-grandparent is enough to increase a person's risk of carrying a Jewish genetic disorder.

YOU HAVE NO FAMILY HISTORY

Disorders can only appear when both parents carry the same disease, but the mutation may pass down for generations without producing an affected child. A couple's risk is based on their genetics.

YOU'VE BEEN TESTED FOR TAY-SACHS

Genetic testing and screening programs have nearly eliminated Tay-Sachs disease in the Jewish community. However, many other serious disorders are linked to Ashkenazi Jews. Sephardic Jews may also be at risk for disorders common to their country of origin.

YOU'RE STARTING A FAMILY USING IVF, DONOR EGGS / SPERM, OR OTHER METHODS

If you discover you're a carrier, you can test donor samples to minimize your risk of having an affected child.

YOUR SIBLINGS AREN'T CARRIERS

We only share a fraction of our genes with our siblings. So even if they screen negative, there is still a chance you may be a carrier for a genetic condition.

YOU WERE SCREENED YEARS AGO

Genetic testing technology has improved dramatically. If you were screened three or more years ago and plan to conceive again, talk to a genetic counselor to see if another test is appropriate.



- jewishgenetics.org
- jewishgenetics@juf.org
- (312) 357-4718
- /jewishgenetics
- @JewishGenetics

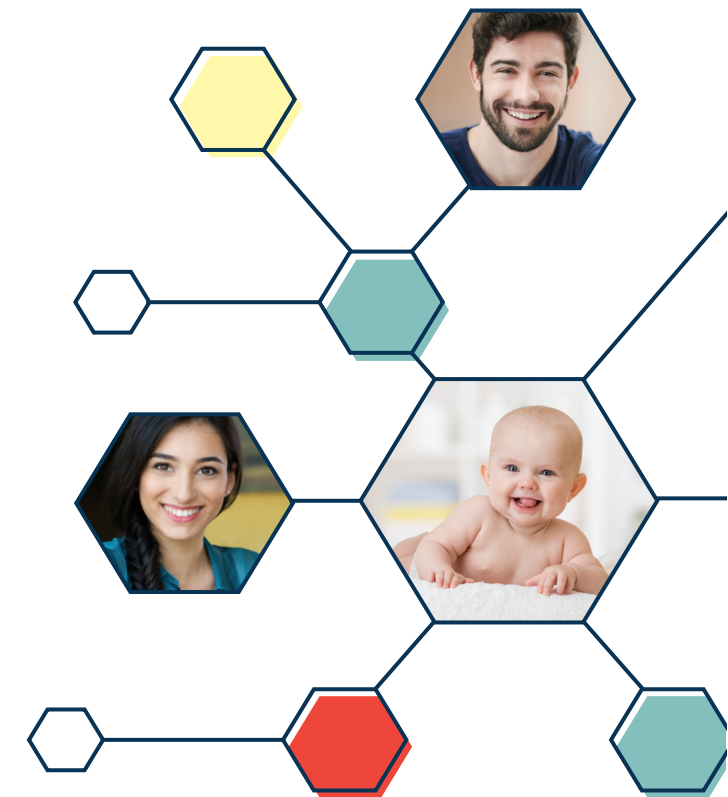


Jewish United Fund
TOGETHER for GOOD

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

JEWISH GENETIC DISORDERS

Get Screened: An Essential Step in Healthy Family Planning



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

