**What You Need To Know For Genetic Carrier Testing**

Before individuals undergo carrier testing at Jewish Genetic Diseases Center Events, it is essential to become familiar with basic information regarding Jewish genetic diseases and how they are inherited. Before they receive their testing kit, individuals will watch an educational genetic video. Then, each participant will be given the opportunity to meet privately with a genetic counselor who will help answer any questions the participant may have and have them sign an Informed Consent before proceeding with the carrier testing.

***If you have any questions about this information or this requirement, please call 480-668-3347 or e-mail******info@jewishgeneticsphx.org******.***

Certain genetic disorders occur with greater frequency in Jewish individuals o than in the larger population. These diseases are therefore known as Jewish genetic diseases. It is important to recognize that they also occur in the larger population, but in a lesser frequency.

Jewish Genetic Diseases can only be detected in one of two ways, through carrier screening or by having an affected child. How would you like to find out?

Because the diseases occur only when each parent of an affected child is a carrier for that particular disorder, there is typically no family history of the disease in either the mother’s family or the father’s family.

**Carriers are healthy individuals who have no symptoms or signs of the disease for which they are carriers.**

The mutated gene that is responsible for the disease may pass from generation to generation and from carrier to carrier with no evidence of the disorder.

**When two carriers for the same disorder become parents of children:**

* There is a 50% likelihood with each pregnancy that the child will be a **carrier** (like each parent),
* There is a 25% likelihood with each pregnancy that the child will be **affected** by the disorder.
* There is a 25% likelihood that the child will be **neither a carrier nor affected** by the disorder.

*If both parents are found to be carriers for the same disorder, it is very important that they seek genetic counseling to learn about options that are available to them to minimize the risk of having an affected child. Genetic counselors are trained to help such families make reproductive decisions that will increase the chances that their children will be healthy.*

**When only one parent is a carrier:**

* There remains a 50% likelihood with each pregnancy that the child will be a carrier (like the carrier parent),
* There is a 50% likelihood with each pregnancy that the child will be a non-carrier (like the non-carrier parent).
* If only one parent is a known carrier, an affected child will occur only when the second parent is also a carrier whose carrier testing failed to detect a disease mutation that was present.

***In order to better understand the risks, genetic counseling is important when one parent is a known carrier.***

***As indicated in the Carrier Frequency Chart, the detection rate for the carrier state for these disorders in the Jewish community is very high, but it is not 100%.***

It is also important to know that with modern technology there is a very high detection rate for the carrier state for these disorders in the Jewish community. The detection rate, however, is never 100%. When the same tests are done on individuals of other ethnic origins, the detection rate may be much lower. Genetic counseling is helpful to more fully understand the implication of both positive and negative carrier tests in different populations. It is important to recognize that the Jewish genetic diseases are generally very serious disorders that may lead to childhood death in some instances and chronic debility and premature death in early adulthood in other instances. None are curable.