Genetic Testing for People of Middle-Eastern Heritage
Iranian-Jewish & Middle Eastern Panels

Advances in genetics have made it possible to diagnose, treat, or prevent certain hereditary disorders. Persons of Middle-Eastern heritage are at higher risk for some genetic disorders than the general world population. Below are seven genetic disorders common in people of Iranian-Jewish decent.

Middle Eastern Genetic Panel Common in Jewish and Non-Jewish Communities	Iranian-Jewish Genetic Panel
Usher Syndrome: Loss of hearing and vision by mid adult age. There is no effective treatment yet.	**Pseudocholinesterase Deficiency:*** Unusual sensitivity to some anesthesia medication. Complications can be avoided before surgery by the selection of appropriate anesthetic drugs.
Beta-Thalassemia: If untreated, may lead to severe anemia, growth retardation and irreversible skeletal malformations, which is preventable by frequent blood transfusions beginning as early as 2 years of age.	**Congenital Hypoaldosteronism:*** Salt loosing disorder, leading to dehydration in infancy. With early on-going simple and inexpensive therapy, a normal life span, growth, and development are expected for affected individuals.
G6PD Deficiency: Blood reaction known as "hemolysis" can occur in response to Fava beans (Favism), to certain other foods, medications, and to infections.	**Polyglandular Deficiency:*** Multiple hormone deficiency that can lead to low calcium, hair loss, and fertility problems. When diagnosed, this disorder is easily treated with hormone replacement therapy.
Hereditary Inclusion Body Myopathy (HIBM) Severe muscle wasting by mid adult age. The children have normal strength. Muscle weakness usually begins by 20 – 30 years of age. It often leads to becoming wheelchair bound by 40-50 years of age. There is no effective treatment, however recent animal studies have offered hope that a treatment may become available in the near future. [1, 2] *Hereditary Inclusion Body Myopathy (HIBM) is included in both panels. Additional information on reverse side.*	

* Testing for these disorders are performed at a reference laboratory

Frequently Asked Questions (FAQ)

- **Is there a requirement to perform the testing?** Currently, there is no requirement to perform the genetic tests to determine if you are a carrier for any of the described genetic conditions. If you do not have any symptoms, you may choose to perform the tests to discover if your children are at risk. If you have symptoms that can be caused by one or more of the conditions, your doctor may order the tests to confirm the diagnosis.
- **Should we consider testing before marriage, after marriage, while planning to have children, or when already expecting (pregnant)?** There is no general consensus regarding when is the best time to perform genetic testing for discovering if your children are at risk. Your genes, your choice.
- **Are the tests covered by insurance?** If you choose to test when planning children or when you are expecting, your insurance may cover some or all of the tests. Your out of pocket expense will depend on the terms of your health insurance.
- **How much does the tests cost?** The cost for each test in the panel may range from about $80 to $650 depending on the method and complexity of each genetic test. When paying out of pocket, we will work with you to make it as affordable as possible.

Contact Information

For more information genetic testing panels for the Middle-Eastern persons, please contact:

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Usher Syndrome: Loss of hearing and vision by mid adult age. Usher syndrome is responsible for the majority of "deaf-blindness" worldwide. There is no effective treatment yet. About one in 25 in Iranian-Jews and one in 50 in Iraqi Jews are carriers. One in 625 Iranian-Jewish couples and one in 2,500 Iraqi-Jewish couples are both carriers, and each of their children has a 25% risk of being affected. [3]

Hereditary Inclusion Body Myopathy (HIBM): Severe muscle wasting leads to becoming physically disabled by mid adult age. The children have normal strength. Muscle weakness usually begins by 20 – 30 years of age. It often leads to becoming wheelchair bound by 40-50 years of age. There is no effective treatment, however recent animal studies by HRG, NIH, and Japanese Investigators have offered hope that a treatment could become available in the near future [1, 2]. In the Iranian-Jewish community one in 15 - 20 persons are carriers, one in 225 – 400 couples are at risk of having an affected child, and based on carrier information about one in 900 – 1,600 is at risk of becoming afflicted. [4]

Beta-Thalassemia: If untreated, may lead to severe anemia, growth retardation and irreversible skeletal malformations, which can be preventable by frequent blood transfusions beginning as early as 2 years of age. Bone marrow transplantation, when successful, may cure the disease. About one in 5 Kurdish Iranian-Jews and one in 25-50 of all Jews of Middle East decent are carriers. Carriers may have mild to moderate anemia. One in 25 Kurdish Iranian-Jewish couples are both carriers, and each of their children has a 25% risk of becoming severely affected. It is also suspected to be common in non-Jewish populations of the Middle East. [5, 6]

G6PD Deficiency: Blood reaction known as "hemolysis" can occur in response to infections, to Fava beans (Favism), and to certain other foods and medications. In severe cases, it can cause acute kidney failure. About one in 7 Iranian-Jews are carriers. Because the disease is "X-linked", each male child has a 50% risk of becoming affected. Female carriers may also become clinically affected. It is also suspected to be very common in non-Jewish populations of the Middle East. [7]

Pseudocholinesterase Deficiency: Unusual sensitivity to some anesthesia medication. This possibly life-threatening sensitivity is preventable by avoiding certain class of medications used in anesthesia. About one in 10 Iranian-Jews are carriers. About one in 100 couples are both carriers, and each of their children has a 25% risk of being affected. [8]

Congentical Hypoaldosteronism: Salt loosing disorder, leading to dehydration in infancy. With early on-going simple and inexpensive therapy, a normal life span, growth, and development are expected for affected individuals. Severity of disease may decrease as children grow up and become adults. About one in 30 Iranian-Jews are carriers, one in 900 Iranian-Jewish couples are both carriers, and each of their children has a 25% risk of being affected. [9]

Polyglandular Deficiency: Multiple hormone deficiency that can lead to low calcium, hair loss, and reversible fertility problems. When diagnosed, this disorder is easily treated with hormone replacement therapy. About one in 50 Iranian-Jews are carriers. About one in 2,500 Iranian-Jewish couples are both carriers, and each of their children has a 25% risk of being affected. [10]

References

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