Tay-Sachs disease

What is Tay-Sachs disease?

Tay-Sachs is an inherited disease of the nervous system which strokes young children. It causes progressive destruction of the central nervous system and death by age 5. It is a disease for which we have no treatment, but are now able to prevent its transmission by testing people to find out if they are carriers.

Tay-Sachs is a recessive genetic disease. That means, in order for a child to have Tay-Sachs disease, they must inherit a Tay-Sachs gene from both parents. In other words, if only one parent is a carrier, they will not have a child with Tay-Sachs disease. If both parents are found to be carriers, testing can be done during pregnancy to determine if the fetus will have Tay-Sachs disease.

Who is at Risk for Being a Carrier of Tay-Sachs disease?

In the general population about 1 out of 200 people is a carrier of Tay-Sachs disease. However, people from certain ethnic groups are much more likely to be carriers of the Tay-Sachs gene.

According to the latest statistics, Jewish people of eastern European ancestry and people of French-Canadian ancestry, especially those from east of the St. Lawrence River, including Cajuns who relocated to Louisiana and Mississippi, all have much greater chance of being carriers; about 1 in 30. Most people in Southern New Hampshire with French last names are of French-Canadian ancestry; if any of your grandparents were French-Canadian, you are in the high-risk group.

The American College of Obstetrics and Gynecologists recommend that all members of these high risk groups be tested for the gene, preferably before pregnancy. It is important to note that 85% of Tay-Sachs disease cases strike families with no prior history of disease.

How Can I Be Tested?

A simple blood test can detect whether or not you are a carrier of the gene. Samples are sent to the Tay-Sachs Prevention Program at the Shriver Center in Waltham, Massachusetts. It is the only testing center in New England approved by the Tay-Sachs & Allied Diseases Association. When pregnant women are tested, the blood testing is more difficult and costly; and results may be inconclusive. Therefore, we usually recommend that the male counterpart be tested first, even if he is not from the high risk carrier group.

Blood can be drawn at the Quest Lab at 300 Main St. Nashua, from 7-11:30 am and 12:30-3:30 pm any weekday. Please let us know if you would like to be tested so that we can authorize the test for you. The cost of the screening is approximately $110.00, including a drawing fee. If you are required to go to the Shriver Center for further testing, the cost is $120.00. Please contact your insurance company regarding coverage.