



Newborn Screening FACT Sheet

FD (HbDD Disease) – Hemoglobin D Disease

What is Hemoglobin?

Hemoglobin is a protein in the red blood cells. It carries oxygen from the lungs to all parts of the body and gives blood its red color. There are many hemoglobin types (this is not the same as a blood type). Hemoglobin is inherited through genes, one from each parent. Most people have hemoglobin A, also called adult hemoglobin.

What is Hemoglobin D Disease (DD)?

Hemoglobin D in the red blood cells is responsible for causing hemoglobin D disease (DD). Children inherit this disease from their parents as a recessive genetic disorder. This means a hemoglobin D gene is passed from both mom and dad to the baby causing DD. Persons with DD have only hemoglobin D and no adult or normal hemoglobin. When both parents have one hemoglobin D gene, there is a 1 in 4 or 25% chance with each pregnancy that an infant will inherit two hemoglobin D genes. There are no serious health problems associated with DD, but the gene for hemoglobin D is passed on from your child to your future grandchildren. DD is not contagious. Most people with DD have mild anemia, which may be associated with a slightly enlarged spleen; but usually they do not have disease symptoms and do not require treatment. Persons with DD usually have red blood cells that are smaller with less color than normal red blood cells. These cells may have an irregular shape because particles inside the red blood cells draw together toward the center of the cells. DD red blood cells look like a bull's eye target with a dark center.

What Problems can DD Cause?

The round shaped hemoglobin D red blood cells are not very flexible in moving through blood vessels and have a smaller outside surface area for carrying oxygen. They are very fragile and are more likely to burst than normal red blood cells. The DD red blood cell's lifespan is shorter (normal blood cells live about 120 days). This leads to mild anemia and decreases the ability of red blood cells to hold onto oxygen. Most people do not have symptoms, but some persons may have mild anemia.

What is the Frequency of DD?

DD is very rare and affects both sexes equally. The disease occurs most often in people whose ancestors come from Pakistan and Northwestern India. It also occurs in people from England, Ireland, Holland, Australia, China, and the Middle East.

What can be done to treat DD?

Treatment is usually not necessary. People with hemoglobin DD disease can expect to lead a normal life.

What is Hemoglobin D/Beta-Thalassemia Disease?

Hemoglobin D/beta-thalassemia disease is a more serious disease than DD. Children with hemoglobin D/beta-thalassemia inherit one gene for hemoglobin D from one parent and one beta-thalassemia gene from the other parent. The beta-thalassemia gene causes the body to make less than the normal amount of hemoglobin. Hemoglobin D/beta-thalassemia disease causes moderate destruction of the red blood cells. Persons who are affected may have a more severe anemia and the spleen may be enlarged. Your baby's doctor will do a complete blood count (CBC) and smear of the red blood cells to look for beta-thalassemia when your baby is approximately 6 to 9 months of age.

What are the Most Important Things to Remember about DD and Hemoglobin D/Beta-Thalassemia Diseases?

Work closely with your child's doctor and hematologist (a doctor who is a blood specialist). Make sure your child has regular checkups with them. Call your child's doctor when you have questions and have your child seen if you have any medical concerns.

How Do I Get More Information about DD?

Talk with your baby's doctor. You may also want to have a genetic consultation for you and your family to see how these diseases might affect future children or grandchildren.