Western Washington

Swedish Medical Center
Perinatal Medicine
1229 Madison St.
Nordstrom Tower, Suite 750
Seattle, WA 98104
Phone: (206)386-2101
Fax: (206)386-6715

Eastside Maternal Fetal Medicine
1110 112th Ave NE, Suite 100
Bellevue, WA 98004
Phone: (425) 888-8111
Fax: (425) 888-8110

Valley Medical Center
Maternal Fetal Medicine
4053 Talbot Road S, #450
Renton, WA 98055
Phone: (425) 889-2210

Seattle Children's Hospital
Medical Genetics Clinic
4800 Sand Point Way NE/PO Box 5371
Seattle, WA 98105-0371
Phone: (206) 987-2665
Fax: (206) 987-2495

Columbia Health Center
Maternal Fetal Medicine
4400 - 37th Avenue South
Seattle, WA 98118
Phone: (206) 290-0650
Fax: (206) 205-0580

Group Health Cooperative
Genetic Services
201 16th Ave E CMB-5
Seattle, WA 98112
Phone: (206) 326-2525
Fax: (206) 326-2010
(For Group Health members only)

Odessa Brown Sickle Cell Clinic
2101 E. Yearly Way
Seattle, WA 98122
Phone: (206) 987-7232
Fax: (206) 326-9764

Beta Thalassemia

Information for parents
about beta thalassemia

Revised January 2013
What is hemoglobin?

Hemoglobin is the part of blood that carries oxygen to all parts of the body. The usual type of hemoglobin is called hemoglobin A. Genes that we inherit from our parents determine what type of and how much hemoglobin we have.

What is beta thalassemia?

Hemoglobin is made up of different parts, including beta globin. Beta globin is produced by two genes and when one or both of these genes are not working properly the body makes less hemoglobin. This is called beta thalassemia and occurs in more than one form. One type of beta thalassemia cannot turn into another. Your child will have that type for his or her entire life.

What is beta thalassemia major?

With this type of beta thalassemia, the genes produce very little beta globin, so the effect on the body is large, or major. This can be a very serious disease that will require regular blood transfusions and other medical treatments.

What is beta thalassemia minor?

With this type of beta thalassemia, the genes produce a larger amount of beta globin (still not enough) and the effect is minor. Although beta thalassemia minor does not cause any health problems, you and your baby's doctor should know that it can cause a mild anemia (low number of red blood cells).

How does this affect the rest of our family?

Beta thalassemia is inherited, so you and other family members could also have beta thalassemia and may want to be tested. It is also important to know about your child's beta thalassemia status because future children in your family may be at risk for the same or a different type of beta thalassemia as this child. To have testing done, talk to your health care provider or one of the genetic counselors listed on the back of this pamphlet.

What is beta thalassemia minor?

With this type of beta thalassemia, the genes produce a larger amount of beta globin (still not enough) and the effect is minor. Although beta thalassemia minor does not cause any health problems, you and your baby's doctor should know that it can cause a mild anemia (low number of red blood cells).

What happens when beta thalassemia is inherited with other abnormal hemoglobins (like Sickle Cell)?

When a person inherits one gene for beta thalassemia from one parent and one gene for sickle hemoglobin (hemoglobin S) from the other parent it is called sickle-beta thalassemia. Sickle-beta thalassemia is similar to sickle cell disease and can cause serious health problems like painful episodes, fatigue, an enlarged spleen, and a higher risk for certain infections. E-beta thalassemia occurs when a person inherits one gene for beta thalassemia from one parent and one gene for hemoglobin E from the other parent. This is also a very serious disorder and will cause severe to moderate anemia. People with sickle-beta thalassemia and E-beta thalassemia should receive regular medical care.

What do I do now?

We recommend that you and your partner have testing done to determine your hemoglobin status. This would provide you with information on your chances of having a future child with beta thalassemia major, sickle-beta thalassemia, or E-beta thalassemia. To have this testing done, talk to your health care provider or one of the genetic counselors listed on the back of this pamphlet. You may also want to share this information with the rest of your family. They may be interested in finding out their hemoglobin status as well.

What can I do if I have more questions?

If you have more questions, you can talk to your child's health care provider or you can contact the Newborn Screening Program using the information below.

Newborn Screening Program
1610 NE 150th Street
Shoreline, WA  98155
Phone: (206) 418-5410
or toll-free 1-866-660-9050
Email: NBS.Prog@doh.wa.gov
Internet: www.doh.wa.gov/nbs