Genetic Counseling Resources for Hemoglobin Disorders and Traits

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) 688-8111 Fax: (425) 688-8110

Evergreen Hospital Medical Center Maternal-Fetal Medicine 12333 NE 130th Ln, Tan 240 Kirkland, WA 98034 Phone: (425) 899-2200 Fax: (425) 889-2210 Valley Medical Center Maternal Fetal Medicine 4033 Talbot Road S, #450 Renton. WA 98055

Seattle Children's Hospital Medical Genetics Clinic 4800 Sand Point Way NE/ PO Box 5371/A7937 Seattle, WA 98105-0371 Phone: (206) 987-2665 Fax: (206) 987-2495

Phone: (425)656-5520

Fax: (425)656-5363

Columbia Health Center 4400 - 37th Avenue South Seattle, WA 98118 Phone: (206) 296-4650 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. Yesler Way Seattle, WA 98122 Phone: (206) 987-7232 Fax: (206) 329-9764 UW Medical Center Medical Genetics Clinic 1959 NE Pacific Street/ Box 357720 Seattle, WA 98195-7720 Phone: (206) 598-4030 Fax: (206) 598-3269

UW Medical Center
Prenatal Diagnosis Clinic
1959 NE Pacific Street/ Box 356159
Seattle, WA 98195

Phone: (206) 598-4072 Fax: (206) 598-2359

Madigan Army Medical Center Medical Genetics 9040 Jackson Ave Tacoma, WA 98432 Phone: (253)403-8674 (Services limited to Armed Services personnel and their dependents)

MultiCare Regional
Maternal-Fetal Medicine
1105 Division Ave, Suite 201
Tacoma, WA 98405
Phone: (253) 403-9200
Fax: (253) 403-9201

Legacy Salmon Creek Medical Center Maternal-Fetal Medicine 2101 NE 139th St. Suite 260 Vancouver, WA 98686 Phone: (360)487-2870 Fax: (360)487-2879

Eastern Washington

Kadlec Medical Center 712 Swift Blvd, Suite 1 Richland, WA 99352 Phone: (509) 942-2821 Fax: (509) 943-1497

Deaconess Perinatal Services 800 W 5th Ave Spokane, WA 99204 Phone: (509) 473-3690 Fax: (509) 473-3692

Central Washington Genetics Program Children's Village 3801 Kem Rd Yakima, WA 98902 Phone: (509) 574-3260 Fax: (509) 574-3210 Providence Genetics Clinic 105 W 8th Ave, Suite 454 Spokane, WA 99204 Phone: (509)474-3810 Fax: (509)474-3811

Pullman Regional Hospital
The Center for Genetics
1620 SE Summit Ct
Pullman, WA 99163
Phone: (509) 332-5106
Fax: (509) 334-5723

Wenatchee Valley Medical Center ATTN: Genetics 820 N Chelan Ave Wenatchee, WA 98801 Phone: (509) 667-7538 Fax: (509) 664-3417

Oregon

Kaiser Permanente Department of Genetics 3325 N. Interstate Ave. Portland, OR 97227 Phone: (503) 331-6593 (For Kaiser members only)

Legacy Emanuel Medical Center Maternal-Fetal Medicine 300 N. Graham Street, Ste 100 Portland, OR 97227 Phone: (503) 413-1122 Fax: (503)413-4238

Northwest Perinatal Center 9701 SW Barnes Road, Ste 299 Portland, OR 97225 Phone: (503) 297-3660 Fax: (503)297-7637

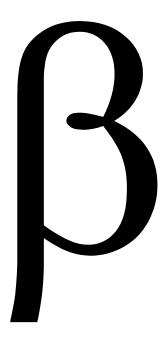
Oregon Health Sciences University Prenatal Diagnosis and Counseling 3181 SW Sam Jackson Park Road **Portland**, OR 97239 Phone: (503) 418-4200

Center for Genetics & Maternal – Fetal Medicine 3355 Riverbend Drive, Suite 210 Springfield, OR 97477 Phone: (541) 349-7600

Revised January 2013



Beta Thalassemia



Information for parents about beta thalassemia

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 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

