

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
Phone: (425)656-5520
Fax: (425)656-5363

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

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)403-3481
Fax: (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 Kern 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

Alpha Thalassemia



Information for parents about
hemoglobin Bart's and alpha
thalassemia

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What is hemoglobin?

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

What is alpha thalassemia?

Hemoglobin is made up of many different parts, including alpha globin. Alpha globin is produced by four genes and when any of those genes are not working properly the body makes less hemoglobin. This is called alpha thalassemia and occurs in four different forms, depending on the number of genes not working. One form of alpha thalassemia cannot turn into another kind. Your child will have that form for his or her entire life.

Why was my child screened for alpha thalassemia?

The Newborn Screening Program screens all infants born in Washington State for certain disorders, including hemoglobin disorders. A small amount of blood was collected from your infant's heel and sent to the State Laboratory for testing. That testing found a higher than normal level of hemoglobin Bart's, a protein that is made when alpha globin genes are not working properly.

What happens when one gene for alpha globin is not working?

A person who has one of the four alpha globin genes not working is called a silent carrier. This form of alpha thalassemia does not cause any major changes in the hemoglobin or any health problems.

What happens when two genes for alpha globin are not working?

A person who has two of the four alpha globin genes not working has alpha thalassemia trait. This form of alpha thalassemia causes only small changes in the hemoglobin and does not cause any health problems.

If one or two non-working genes for alpha globin do not cause any health problems, why do I need to know that my child has alpha thalassemia?

Although one or two non-working alpha globin genes do 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). It is also important to know about your child's alpha thalassemia status because future children in your family, or other family members, may be at risk for more serious forms of alpha thalassemia, which are described on the next page. Also, people with the silent carrier form or alpha thalassemia trait can pass the gene(s) to their children.

What happens when three or four genes for alpha globin are not working?

If a person has three non-working genes, it will result in hemoglobin H disease. Hemoglobin H disease can sometimes cause serious health problems due to moderate or marked anemia and should be followed regularly by a doctor. People with four non-working genes are unable to produce the hemoglobin needed to live. This is called alpha thalassemia major. This is not what your child has. This form causes death in the affected individual before or soon after birth. If your doctor or genetic counselor feels that you are at risk for having a baby with either of these forms of alpha thalassemia, they will provide you with more information.

What do I do now?

Your baby's doctor may do more testing on your baby to clarify which form of alpha thalassemia your baby has (whether one or two genes are not working). This will involve drawing a small amount of blood from your baby. It is also recommended that you and your partner have testing done to determine your hemoglobin status. This would provide information on your chances of having a future child with a more serious form of alpha 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
Toll Free: 1-866-660-9050
Email: NBS.Prog@doh.wa.gov
Internet: www.doh.wa.gov/nbs

