



## **Hemoglobin E Disease**

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### **What is it?**

Hemoglobin E disease is an inherited red blood cell abnormality. It is usually not serious and does not often cause health problems.

Hemoglobin E disease is common in people whose ancestors are from Southeast Asia, especially Cambodia, Laos and Thailand.

Some babies who are positive for hemoglobin E disease have a much more serious disease called hemoglobin E/beta-thalassemia. It is important to find babies with hemoglobin E/beta-thalassemia. These babies may need to go to a special doctor. All babies who are positive for hemoglobin E disease should have a special blood test when they are 4 to 6 months old. This test will help to rule out hemoglobin E/beta-thalassemia.

### **What causes it?**

Hemoglobin E disease is inherited when both parents pass on a gene for hemoglobin E to their child. This means both parents carry at least one gene for hemoglobin E. A person who carries one gene for hemoglobin E has hemoglobin E trait. Because hemoglobin E disease does not cause any health problems, a parent may have hemoglobin E trait or hemoglobin E disease and not even know it.

### **How is hemoglobin E disease detected?**

The testing is done on tiny samples of blood taken from the baby's heel after birth. If the screening shows hemoglobin E, a special blood test must be done when the baby is 4 to 6 months old to make sure the baby does not have hemoglobin E/beta-thalassemia disease.

### **What problems can it cause?**

Most people with hemoglobin E disease do not have any problems. They may have some slight blood abnormalities on a blood test, but they do not require treatment. These blood abnormalities include anemia (too few red blood cells) and small red blood cells. People with hemoglobin E/beta-thalassemia disease can have serious symptoms and may need many blood transfusions.

### **How is it treated?**

Most people do not need any treatment. Doctors do not use iron medicine to treat the anemia caused by hemoglobin E disease. It is important to let your doctor know that your baby has hemoglobin E disease to avoid unnecessary iron medicine.

### **Hemoglobin E disease in children?**

All babies with hemoglobin E results on a newborn screening test should have testing when they are 4 to 6 months old to check for hemoglobin E/beta-thalassemia.

Babies with hemoglobin E/beta-thalassemia must see a special doctor called a pediatric hematologist.

Close family members of babies with hemoglobin E/beta-thalassemia may need to be tested to learn their hemoglobin type.

### **Where can I find more information?**

University of Rochester Medical Center  
[www.urmc.rochester.edu/genetics/hemo.htm](http://www.urmc.rochester.edu/genetics/hemo.htm)

Washington State Department of Health  
[www.doh.wa.gov/EHSPHL/PHL/newborn/reports.htm#HB](http://www.doh.wa.gov/EHSPHL/PHL/newborn/reports.htm#HB)

### Children's Special Health Services (CSHS)

State Capitol Judicial Wing  
600 E. Boulevard Ave., Department 301  
Bismarck, ND 58505-0269  
Toll Free: 800.755.2714  
701.328.2436  
Relay TDD: 701.328.3975  
CSHS website: [www.ndhealth.gov/CSHS](http://www.ndhealth.gov/CSHS)  
North Dakota Department of Health website:  
[www.ndhealth.gov](http://www.ndhealth.gov)

#### Family support resources available from CSHS:

- Guidelines of Care Info
- Family Support Packet
- Financial Help Packet
- Insurance Fact Sheet

#### *Family Resources*

Family to Family Network  
Center for Rural Health  
University of North Dakota  
School of Medicine and Health Sciences  
P.O. Box 9037  
Grand Forks, ND 58202-9037  
Toll Free: 888.434.7436  
701.777.2359  
Fax: 701.777.2353  
E-mail: [NDF2F@medicine.nodak.edu](mailto:NDF2F@medicine.nodak.edu)  
[www.medicine.nodak.edu/crh](http://www.medicine.nodak.edu/crh)

Pathfinder Services of ND  
Pathfinder Family Center  
1600 2<sup>nd</sup> Ave. SW, Ste. 19  
Minot, ND 58701  
Toll Free: 800.245.5840  
701.837.7500  
Relay TDD: 701.837.7501  
E-mail: [ndpath01@ndak.net](mailto:ndpath01@ndak.net)  
[www.pathfinder.minot.com](http://www.pathfinder.minot.com)

Family Voices of North Dakota, Inc.  
P.O. Box 163  
Edgeley, ND 58433  
Toll Free: 888.522.9654  
701.493.2634  
Fax: 701.493.2635  
[www.geocities.com/ndfv](http://www.geocities.com/ndfv)

\*\*This fact sheet has general information. Every child is different and some of these facts may not apply to your child specifically. Certain treatments may be recommended for some children but not others. All children should be followed by a metabolic doctor in addition to their primary-care provider.

#### **Acknowledgement**

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#### **Disclaimer**

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