

## The Iowa Hemoglobinopathy Screening and Comprehensive Care Program

Serves all Iowa children and adults with hemoglobinopathies. Its main office is located in Iowa City, but services are available to anyone, anywhere in the state.

### What does the Iowa Hemoglobinopathy Screening and Comprehensive Care Program provide?

- Screening to all newborn infants in Iowa for hemoglobin disorders.
- Comprehensive medical care to children and adults with hemoglobinopathies.
- Information, testing, counseling and educational materials.
- Medical specialists who travel to towns and cities throughout Iowa to provide services.
- Coordination of services and consultation to local doctors, clinics, and hospitals in Iowa.
- Screening of family members and genetic counseling.

### Is it expensive for me to use the Iowa Hemoglobinopathy Screening and Comprehensive Care Program?

The program provides initial advice and information regarding resources free of charge.

UNIVERSITY of IOWA  
HEALTH CARE

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## The Iowa Hemoglobinopathy Screening and Comprehensive Care Program

A program of The University of Iowa  
Department of Pediatrics  
*in cooperation with the*  
Iowa Neonatal Metabolic Screening Program  
The University of Iowa  
Child Health Specialty Clinics  
The Department of Internal Medicine

## What is a hemoglobinopathy?

Hemoglobinopathy is a disorder involving hemoglobin. Hemoglobin is the protein present in red blood cells which carries oxygen and which gives blood its color. There are different types of hemoglobinopathies:

*Sickle cell anemia* is one of the most common hemoglobinopathies. This disease causes misshaped (sickle) red blood cells which can clog small vessels, disrupting the delivery of oxygen to the body tissues. This can cause such problems as pain, infection, lung complications, kidney problems, stroke, and other medical problems. Medical care, parent education, and antibiotics can minimize life-threatening complications.

Individuals who have *sickle cell trait* have one normal hemoglobin gene and one abnormal (sickle) gene. They do NOT have a disease and usually have no medical problems related to their condition; however, they can pass the trait on to their children through their genes. Genetic counseling can tell couples how likely this is to happen.

Individuals who have *thalassemia* have a decreased amount of hemoglobin. The thalassemias, alpha and beta, affect different people in various ways.

Some people may be completely well and require no special medical care while others need special care including red blood cell transfusions.

## Who is affected by hemoglobinopathies?

While various hemoglobinopathies tend to be concentrated in particular racial or ethnic groups, any person can be affected.

## Why must I treat the hemoglobinopathy?

Serious medical problems can result from hemoglobinopathies. In some cases, the complications can be life-threatening. Early intervention can greatly reduce complications. Ongoing treatment is important to decrease the risk of infection, minimize painful episodes, and improve the quality of life.

## How will I know if my baby has a hemoglobinopathy?

Iowa law requires that a tiny amount of blood be taken from every newborn baby shortly after birth. A state-approved laboratory analyzes the blood for hemoglobinopathies and other inherited

diseases and sends a report to your doctor. In addition, the Hemoglobinopathy Screening and Comprehensive Care Program will contact you and/or your doctor.

## Need information?

Please contact  
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