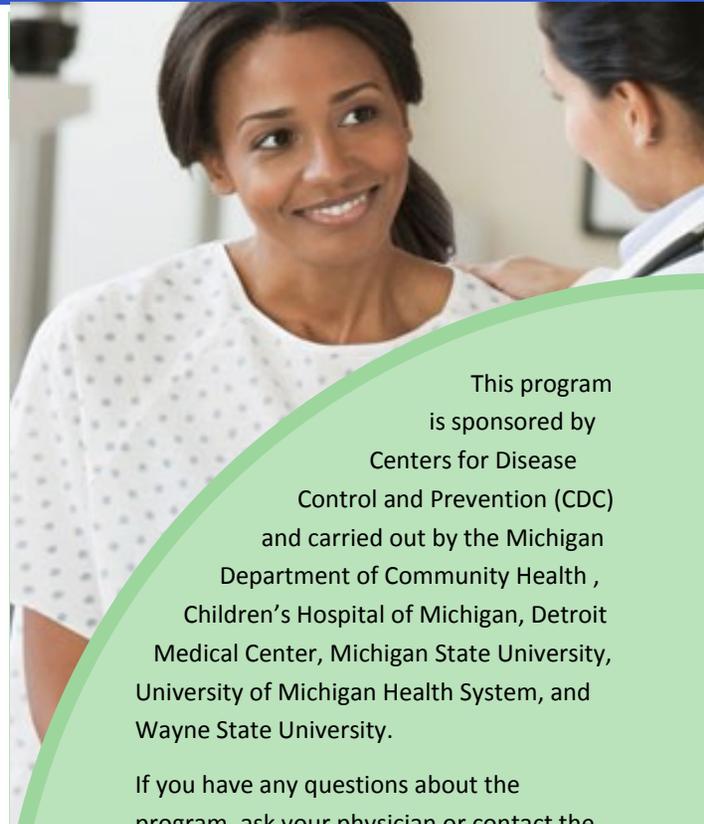




WHAT ARE MY RIGHTS AS A PARTICIPANT?

- Your relationship with the physician and staff will not be affected if you do not want to take part in this program, or decide to withdraw from it.
- You can tell your doctor not to use or give out information from your medical record to other people or companies at any time. Withdrawal must be in writing.
- Any program information or other information from your medical record collected before your written notice of permission withdrawal may still be used for the program, if that information is necessary for the program.
- You will not be able to look at or ask for a copy of your health information collected for this program while you are taking part in the study. This does not affect your right to see your medical record or test results during the same time .



This program is sponsored by Centers for Disease Control and Prevention (CDC) and carried out by the Michigan Department of Community Health , Children’s Hospital of Michigan, Detroit Medical Center, Michigan State University, University of Michigan Health System, and Wayne State University.

If you have any questions about the program, ask your physician or contact the Michigan Department of Community Health Lifecourse Epidemiology & Genomics Division at 1-866-673-9939.

<http://www.michigan.gov/nbs>

Keep Michigan on the lookout



The safety of blood products is crucial for people with sickle cell disease and thalassemia. Find out how you can help keep Michigan’s blood supply safe.





Michigan Blood Safety Surveillance among People with Blood Disorders



It's important to monitor the safety of blood products in the people who use them most. As a patient with sickle cell disease or thalassemia who receives transfusions, you can help Michigan keep our blood safe.

ABOUT THE PROGRAM

The purpose of this program will be to monitor the safety of the nation's blood supply and meet the shifting priorities of blood safety within heavily transfused patient populations. Michigan hospitals are participating as part of a larger study in multiple centers throughout the US.

Transfusions can become a major source of complications for people with blood disorders. There is no natural way for the body to eliminate iron, so iron in the transfused blood cells builds up and becomes toxic to tissues and organs, particularly the liver and heart.

Blood in transfusions is highly tested and very safe. But rarely, frequent blood transfusions can also expose people to infections that may be transmitted through blood. Blood donors are screened for a number of known infectious diseases, but occasional new infectious agents

can be missed by this screening. While your hospital is testing for a lot of these, the CDC would like to do a national test as added protection.

It is your choice whether you decide participate in the study or not.

WHAT DO I HAVE TO DO?

Provide a blood sample during your transfusion procedure.

Answer questions related to your health status and difficulties caused by sickle cell disease of thalassemia.

Your answers will be used to help plan programs and reduce or prevent problems for other people with similar diseases or treatments.

WHERE WILL MY BLOOD GO?

By taking part in this program, you are agreeing to let CDC save what is left of your blood sample after the initial viral testing is done. We will add your sample to a collection

of blood samples donated by other persons into a serum bank. We will use this serum bank to look for diseases in blood that might affect most people with blood diseases. We will also use it to look for diseases in blood that could harm anyone who gets blood.

WHO WILL SEE MY PRIVATE INFORMATION?

Your physician and the Michigan Department of Community Health will delete any identifying information (name, address, and birthday) before sending your blood and survey responses to the CDC. Your information will be stored in a secure password-protected system. The records of this program will be kept confidential with respect to any written or oral reports to the profession or the media, making it impossible to identify you individually.

