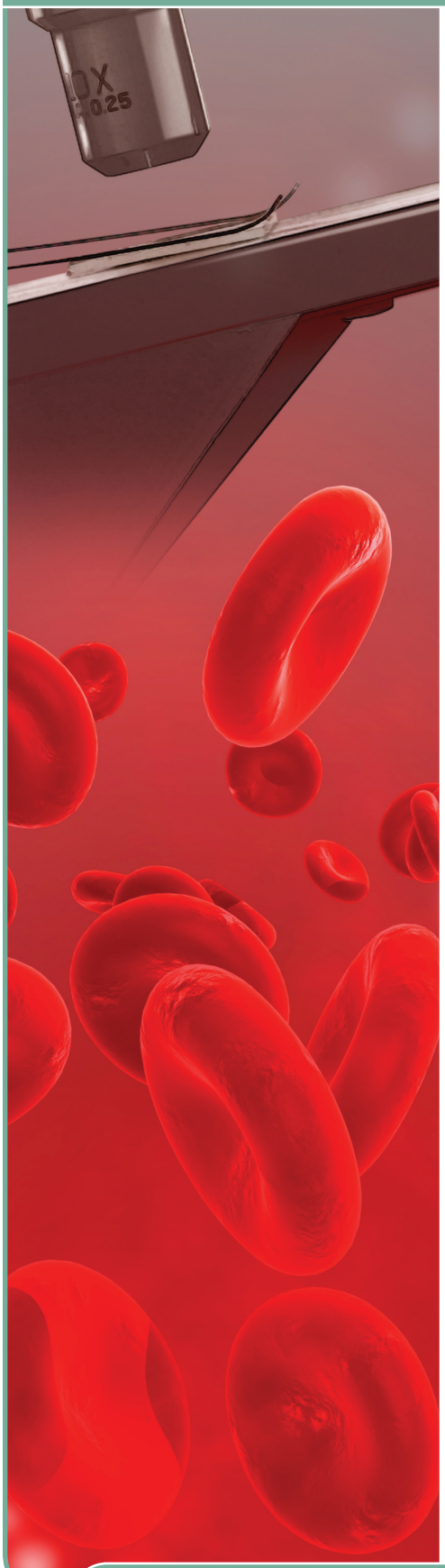
Registry and Surveillance System for Hemoglobinopathies (RuSH)



What are Hemoglobinopathies?

Hemoglobinopathies is the medical term for a group of blood disorders and diseases that affect red blood cells. These disorders include both sickle cell disease (SCD) and thalassemia. Inherited disorders such as these can cause lifelong disabilities and reduce life expectancy.

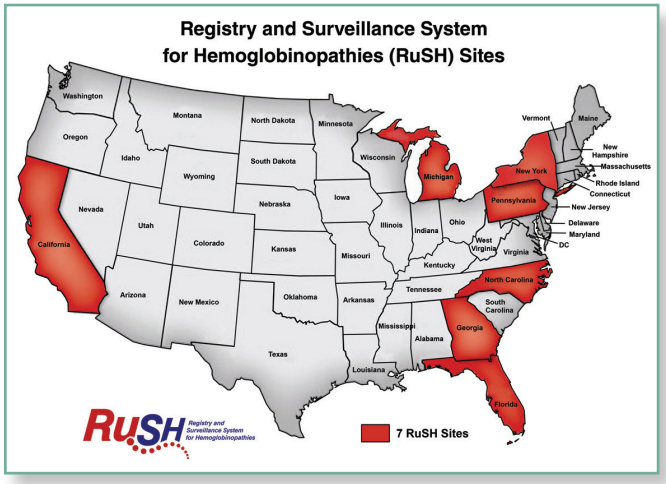
People with sickle cell disease produce red blood cells that become hard and sticky and look like a C shaped farm tool called a "sickle". The sickle cells tend to grow and die early, which causes a constant shortage of red blood cells. Also, when they travel through small blood vessels, these cells can get stuck and clog the blood flow. This can cause health problems such as chronic pain, infections, and stroke.

People with thalassemia have a genetic defect in their red blood cells that affects the ability of the cells to produce normal hemoglobin. Red blood cells use hemoglobin to carry oxygen to different parts of the body. As a result of the defect, most forms of thalassemia produce a lifelong anemia (a reduced number of red blood cells) that begins shortly after birth and often must be treated with transfusions.

There is little information about how many people are living with SCD and thalassemia, where they receive their medical care, and the health problems that they experience over the course of their life. We at the Centers for Disease Control and Prevention (CDC) are working to find out about these and other issues related to SCD and thalassemia.

What is RuSH?

The Registry and Surveillance System for Hemoglobinopathies (RuSH) is designed to collect information to learn about the number of people living with SCD and thalassemia so that we can better understand how these disorders affect their health.



RuSH is being coordinated by CDC in collaboration with the National Institutes of Health (NIH) and seven pilot states (California, Florida, Georgia, North Carolina, New York, Michigan and Pennsylvania). The first step is to better understand the information already being collected by the pilot states, as well as the methods being used to collect the information. This information then can be put together to more adequately describe the health of people with SCD or thalassemia.

National Center on Birth Defects and Developmental Disorders
Division of Blood Disorders

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What are the goals of RuSH?

The immediate goals of the RuSH pilot project are to:

- Determine how many people have SCD or thalassemia.
- Develop plans for a national surveillance system to gain a greater understanding of the health status and health practices of people living with SCD and thalassemia.
- Develop health education materials to increase knowledge and awareness about SCD and thalassemia among the general public.

What type of information will be collected?

Each state public health department routinely collects data that provide information about the people who live in that state. State-based information includes vital records (such as births, deaths, pregnancies, and pregnancy outcomes); communicable disease data (diseases that can be passed from person to person); immunization records (shots given to prevent diseases); newborn screening results; and health care statistics such as hospitalizations and sources of medical care. However, not every state collects the same information or collects the information in the same way. By standardizing the public health data collected in the pilot states, the RuSH program will lead to a better understanding of the health of people with SCD or thalassemia.

How will the information collected benefit people with SCD and thalassemia?

Neither CDC nor NIH will have any identifying information on individual RuSH participants. However, by collecting more state-specific information, we hope to improve the quality of life for people living with these disorders. The information will be used to:

- Identify those communities that are in need of greater medical resources to address SCD and thalassemia.
- Monitor how SCD and thalassemia affect people across their lifespan.
- Identify the medical and social needs of people with SCD and thalassemia across their lifespan.

How can I get more information about RuSH?

If you would like more information about the RuSH program, please visit www.cdc.gov/sicklecell/ or send an email to cdcinfo@cdc.gov