Sickle SAFE Program

Serving Indiana's Children & Families

What is Sickle SAFE?

The mission of the *Sickle SAFE Program* is to provide early screening and promote assessment, follow-up, and educational services for infants with sickle cell disease and their families.

The program is committed to improving the quality of life and productivity of individuals with sickle cell disease through a comprehensive, patient/family focused health care delivery system that integrates local community resources.

The *Sickle SAFE Program* is funded by the Indiana State Department of Health Newborn Screening Program.

What is sickle cell disease?

The *Sickle SAFE Program* was developed by the Indiana Hemophilia and Thrombosis Center, Inc. This program enhances the follow-up care for infants born in Indiana with sickle cell disease through:

Screening
Assessment
Follow-up and
Education

Every year in Indiana, approximately 30 newborns test positive for a type of hemoglobin disease like sickle cell disease, and 1 in 10 newborns are born with sickle cell trait or an inherited abnormal hemoglobin. Early diagnosis and education for parents provides the knowledge needed to help ensure optimal care for their child.

The Sickle SAFE staff work closely with hematologists around the state to ensure infants have a local medical network for health maintenance and treatment of complications related to the disorder.

What are the program components?

SCREENING
Since 1985, all infants born in Indiana are tested for abnormal hemoglobins.

All infants testing positive for sickle cell disease or another hemoglobin disease are referred to the *Sickle SAFE Program* by the Indiana State Department of Health Newborn Screening Program.

ASSESSMENT
Assessments are conducted to determine each family's level of knowledge about sickle cell disease, and to help identify additional social and environmental needs. Referrals are then coordinated as needed.

FOLLOW-UP
Follow-up services are provided for a minimum of five years to assure families have access to the highest level of care available throughout Indiana.

EDUCATION
The program strives to develop a positive relationship with all referred families. Education is tailored to each individual family and provided at initial and subsequent encounters.

Who is at risk?

In the United States, Sickle Cell disease is most common in African Americans and persons of Mediterranean, Middle Eastern, and American Indian ancestry. It also affects other groups including Latinos and Asians. A growing number of Caucasian Americans in the United States are being identified with sickle cell trait (carrier) and other abnormal hemoglobins.

There are an estimated 100,000 people living with a type of sickle cell disease and over 2 million people with sickle cell trait in the US alone.

Indiana Sickle Cell Centers

Indiana Hemophilia & Thrombosis Center, Inc.
8326 Naab Road
Indianapolis, Indiana 46260
317-871-0000
877-256-8837

Riley Pediatric Sickle Cell Center
Riley Hospital for Children | Riley Outpatient Center
702 Barnhill Drive, 3rd Floor
Indianapolis, Indiana 46201
317-944-2143
800-248-1199

Lutheran Hospital of Indiana
Children's Hospital
Pediatric Hematology/Oncology Clinic
7950 West Jefferson Boulevard
Fort Wayne, Indiana 46804
260-435-2501
800-444-2001

Memorial Children's Hospital
Pediatric Hematology/Oncology Clinic
615 North Michigan Street, 6th Floor
South Bend, Indiana 46601
574-647-6892
800-284-6892

Sickle Cell Advocacy Centers

The Martin Center Sickle Cell Initiative
3545 North College Avenue
Indianapolis, Indiana 46205
317-927-5158
888-658-7719

North Central Indiana Sickle Cell Initiative
Community Health Enhancement
615 North Michigan Street
South Bend, Indiana 46601
574-647-1350

SCACure Networks, Inc.
815 John Street, Suite 110
Evansville, IN 47713

INDIANA HEMOPHILIA & THROMBOSIS CENTER, INC.

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