Services & Support

SCACURE PROVIDES THE FOLLOWING SERVICES AND SUPPORT:

NEWBORN SCREENING - With funding and resources from the Indiana State Department of Health, we inform parents of babies born with sickle cell trait in the Southern Indiana region and confirm primary care physicians. We strive to ensure timely follow-up and to provide educational services.

EDUCATIONAL WORKSHOPS - We provide basic education about sickle cell to a broad network of families, advocates, and service providers in the communities we serve.

COMMUNITY ENGAGEMENT - Engaging the broader community in advocacy efforts to support those affected by sickle cell who are underserved or unserved.

SPECIAL PROJECTS - Engaging in grant-supported service projects to help advance care and support for those with Sickle Cell Disease.

SCACURE Envisions...

- Sickle Cell is only a disease that one has; not a definition of one's life.
- Awareness about Sickle Cell is equivalent to that of Autism, Breast Cancer, and Juvenile Diabetes.
- Educational and psychosocial resources are easy to find and readily available.
- Funding to support the needs of those in this life journey with Sickle Cell Disease is available and attainable.
- Sickle Cell Anemia Cure (SCACURE) is no longer a dream, but a reality.

Partners Working For You

Indiana Hemophilia and Thrombosis Center
Indianapolis, Indiana
317-871-0000
www.ihtc.org

Indiana Sickle Cell Consortium
www.indianasicklecell.org

Indiana State Department of Health, Sickle Cell Program
Indianapolis, Indiana
Toll Free: (888) 815-0006

IU School of Public Health
Indianapolis, Indiana
calawren@indiana.edu
Toll Free: 800-566-8644

Martin Center Sickle Cell Initiative
Indianapolis, Indiana
317-927-5158
www.themartincenter.org

North Central Indiana Sickle Cell Initiative
South Bend, Indiana
Toll Free: (877) 647-1370
www.beaconhealthsystem.org/community-outreach

Riley Hospital for Children
Indianapolis, Indiana
317-948-1234
Www.rileychildrens.org/health-info/sickle-cell-disease

Apostello Clothing Co.
Orlando, Florida
www.apostelloclothing.com

Join Our Network:

Join Bone Marrow Registry
Give Blood
Learn More About Sickle Cell Disease
Make A Donation & Volunteer

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

SICKLE CELL FACTS— DID YOU KNOW?

Over 100,000 people in the United States (US) have SCD and over 2 million have Sickle Cell Trait (SCT).

1 in 12 African Americans have SCT and 1 in 400 have SCD.

Sickle Cell affects people of ALL races and ethnicities. For example, every month, SCACURE processes newborn screens for babies of Hispanic ethnicity and from the white and other races.

Currently there is no universal cure for sickle cell disease. For qualified patients, bone marrow transplant may be an option.

All babies are tested for SCD and SCT at birth in Indiana and most states across the U.S.

Everyone needs to know if they have SCT even if they do not get sick.

Putting ice on injuries or swelling is never a good treatment option for those with sickle cell.

Contact Us:

SCACURE
@SCACURE
SCACURE

SCACURE NETWORKS

Advocating for
Sickle Cell Patients and Caregivers

Email:
support@scacurenetworks.org
Toll Free 844-344-6844 or
812-549-3593

Office:
815 John Street, Suite 110
Evansville, IN 47713

Satellite:
11650 Olio Road, Ste. 1000-164
Fishers, IN 46037

Hours: by appointment

www.scacurenetworks.org

SCACURE Networks, Inc. was established to address the needs of the Sickle Cell Community of 24 Counties throughout Southern Indiana; as of 2017, we now serve over 30 counties.

SCACURE stands for "**S**ickle **C**ell **A**nemia **CURE**" consistent with the organization's advocacy efforts to educate, engage, and empower those affected by Sickle Cell Disease and other hemoglobinopathies.

WELCOME TO YOUR NETWORK

What We Do

EDUCATE ALL stakeholders in the Sickle Cell community on the basics of Sickle Cell including what the disease is, how it impacts quality of life, how to manage key relationships for the best care, do's and don'ts in medical care, and why this journey goes beyond the patients and parents.

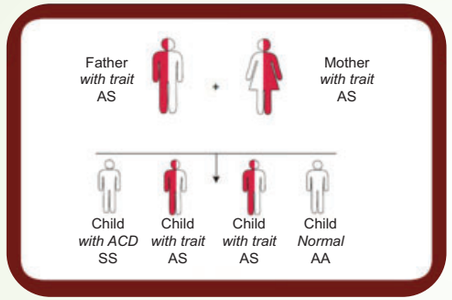
ENGAGE patients, caregivers, friends, medical providers and communities as a whole in the journey to triumph over Sickle Cell Disease even before it becomes a part of life.

EMPOWER patients and caregivers from pre-conception and newborn screening through one's life-cycle to be proactive when possible and to manage overall life effectively.

Sickle Cell Disease

What Is It?

Sickle cell disease (SCD) is a blood disorder that affects the red blood cells. Each newborn inherits two hemoglobin genes, one from each parent: a normal gene that makes normal hemoglobin (A) and an abnormal gene that makes sickled hemoglobin (S). The abnormal hemoglobin causes the red blood cells to be a crescent shape and become hard. These cells then have difficulty traveling through small blood vessels, blocking the flow of blood and the ability for oxygen to get to the body's organs. This blockage causes intense pain and other health problems. Also, the abnormal cells die early, leaving a shortage of healthy blood cells (sickle cell anemia).



The most common types of sickle cell disease are hemoglobin SS, hemoglobin SC and sickle beta thalassemia. It inherited much like eye color and hair color. It is not a disease that you "catch" from another person.

Complications and Symptoms of Sickle Cell

What are the potential health problems of Sickle Cell Disease?

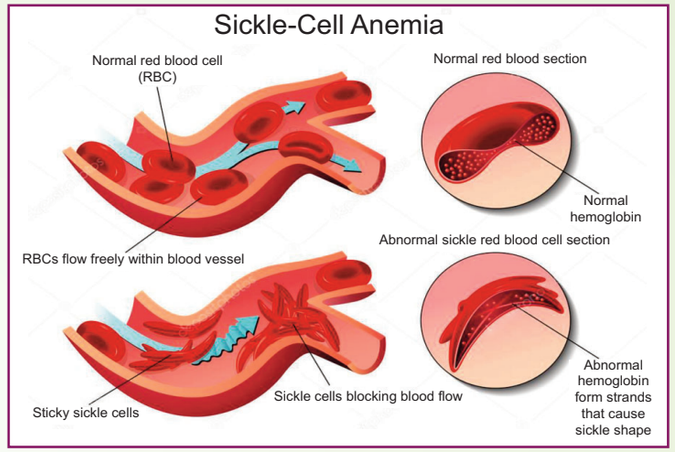
ANEMIA: Sickle cells do not live as long as normal red blood cells. This causes anemia, or a low blood count which can cause weakness and fatigue.

INFECTIONS: Sickle cells may get caught in the spleen causing people with sickle cell disease to be more likely to get infections.

PAIN: Sickle cells that get caught in the small blood vessels of the body cause the interruption of oxygen and blood flow; these sickling crises can be very painful. This includes pain and swelling of the hands and feet in small children.

ACUTE CHEST SYNDROME: Blockage of the flow of blood to the lungs can cause acute chest syndrome (ACS). ACS is similar to pneumonia; symptoms include chest pain, coughing, difficulty breathing, and fever. It can be life threatening and should be treated in a hospital.

ORGAN DAMAGE: Some people have sickle cells that cause the spleen not to function properly. The spleen helps the body fight infections by filtering the blood. If blood transfusions can't help the spleen function improve, then it may need to be removed by surgery.



STROKE: Sickle cells can prevent blood from flowing to the brain and cause a stroke which can result in life-long disabilities and learning problems. Children under 16 are at the highest risk for stroke. With proper care from a hematologist, these children are scheduled for a brain scan each year up to age 16.

LEG ULCERS: Sickle cells block blood vessels and cause poor circulation, sometime leading to sores that are difficult to heal. These often occur around the ankles.

COMPLICATIONS DURING PREGNANCY: A woman with sickle cell disease can have a healthy baby. However, risks are involved; both she and the baby should be closely monitored by a healthcare provider. Prenatal care is very important!

JAUNDICE: The rapid breakdown and short life of sickle cells causes yellowing of the eyes and skin. This is called jaundice, a painless result of the disease.

How is Sickle Cell Disease Managed?

Routine care is very important! Every patient should have a primary care provider, a hematologist, and other specialty care providers that may include a pulmonologist for lung function, an ophthalmologist for vision maintenance, a trusted pharmacist, etc.

Depending on the severity of pain and complication, types of treatments may include blood transfusions or medication:

- Hydroxyurea which increases the body's level of fetal hemoglobin to minimize or prevent sickle cells;
- antibiotics such as a prophylactic dose of Penicillin for infections or prevention of infections;
- Folic Acid to support eye/vision health;
- anti-inflammatory medications and pain medications such as Tylenol or stronger ones given in the hospital by medical staff

Other treatments may not include medication:

- Heat therapy, using a heating pad (not too hot)
- Warm water therapy
- Meditation/relaxation exercises and stretching
- Massage therapy

Everyone should eat a balanced diet, and receive regular check-ups and immunizations. Children with sickle cell disease require a few special immunizations. A yearly flu shot is also recommended.