The Sickle Cell Association of Kentuckiana

SICKLE CELL ANEMIA

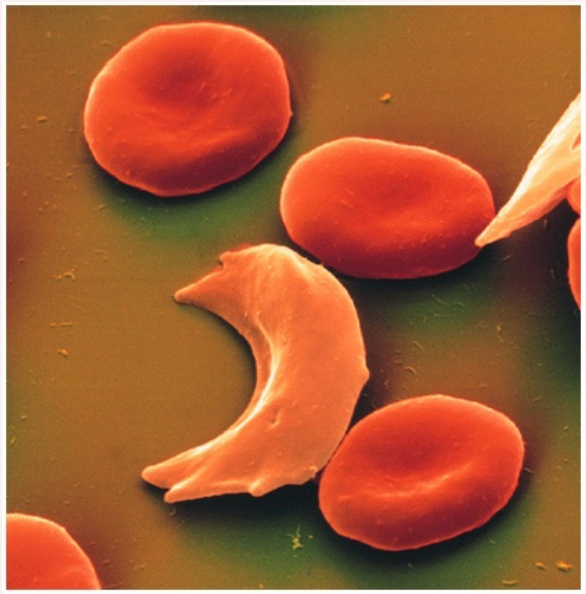
Wednesday, November 13, 2019

Who We Are…

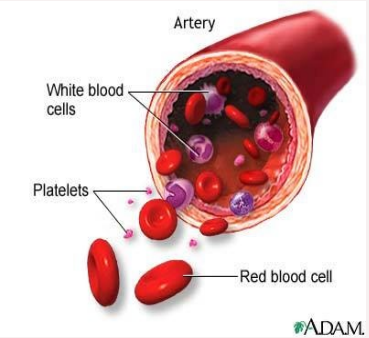
The Sickle Cell Association of Kentuckiana, Inc. (SCAK) is a tax-exempt, not-for-profit organization that provides education, support, and advocacy for individuals with sickle cell disease and their families. SCAK is dedicated to increasing awareness of this disease and supporting endeavors that assure prompt and appropriate medical care. Our mission encompasses educating the lay community as well as the medical community about the disease and resource availability. In addition our organization has a commitment to the children and adults in this community to provide needed items to improve their quality of life, increase opportunities to live as productive citizens, and expel the negative assumptions that go with the stigma of living with sickle cell disease. The goal of the Sickle Cell Association is to establish a Center of Excellence in Kentucky to, not only treat those who need our services now, but to ensure that those services are available in the future.

What is Sickle Cell Anemia (SCA) ?

Sickle Cell is an inherited blood disorder that affects the red blood cells.



Causes



✓Hemoglobin is a protein inside red blood cells that carries oxygen.

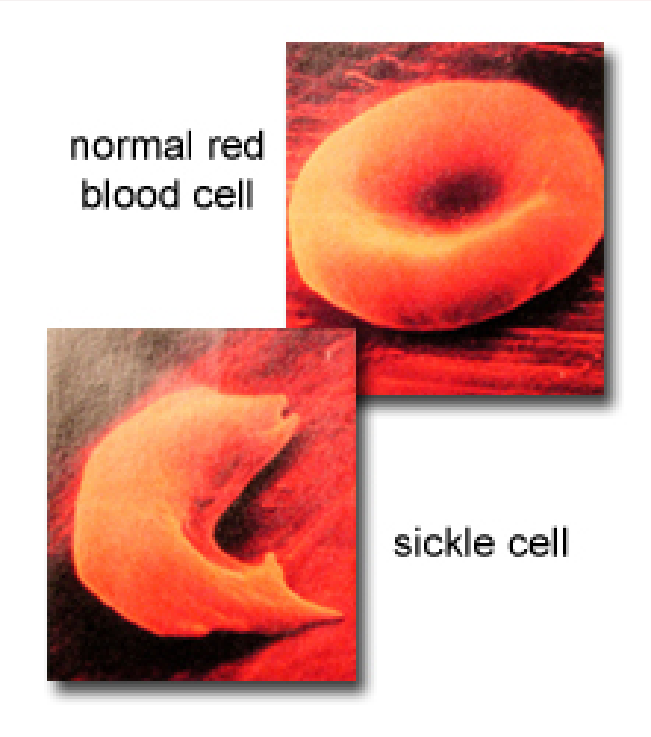
✓Hemoglobin S changes the shape of red blood cells, especially when the cells are exposed to low oxygen levels.

✓The red blood cells become shaped like crescents or sickles.

✓The fragile, sickle-shaped cells deliver less oxygen to the body's tissues.

✓They can also get stuck more easily in small blood vessels, and break into pieces that interrupt healthy blood flow.

Sickle Cell Anemia

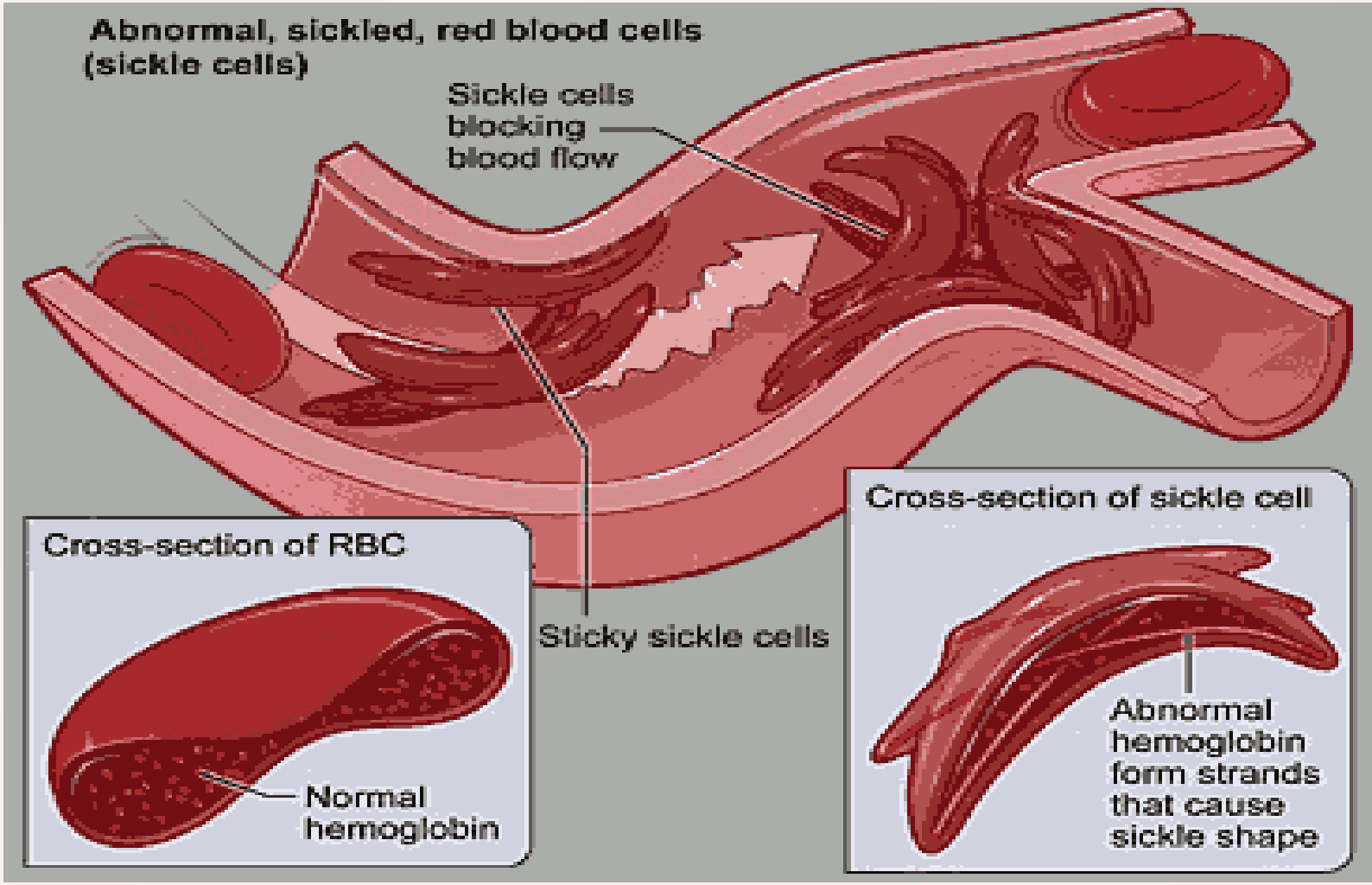


✓Person without Sickle Cell would have 100% round shaped red blood cells.

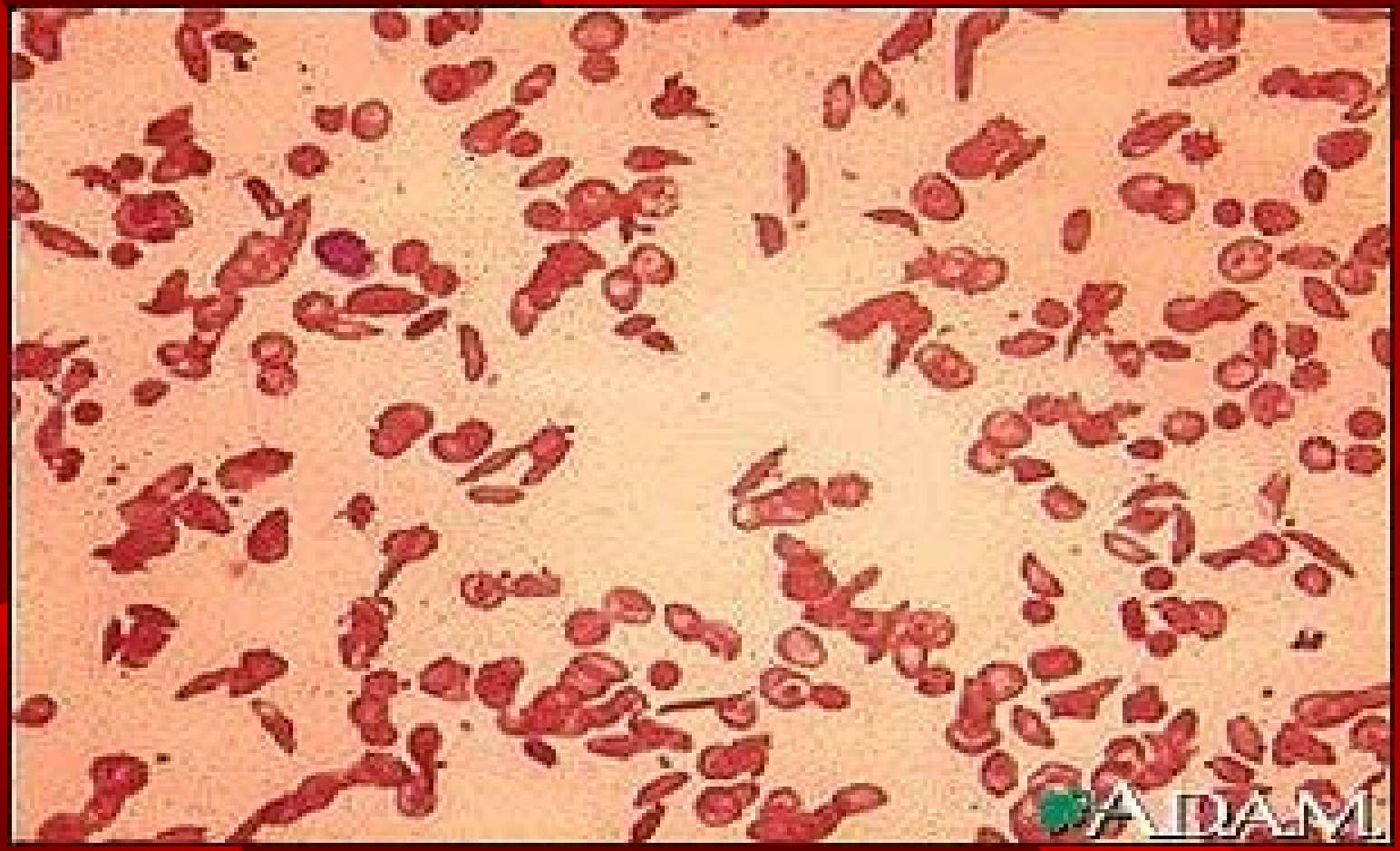
✓Person with Sickle Cell trait (carrier) would have 80% round red blood cells and about 20% sickle shaped red blood cells.

✓Sickle Cell patient would have over 60% sickle shaped red blood cells.

What's Happening … (cont.)



Sickle Cell Anemia



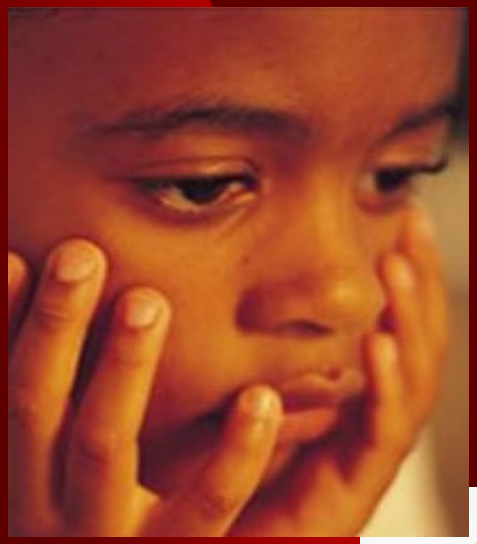
Who in the world does SCA affect…

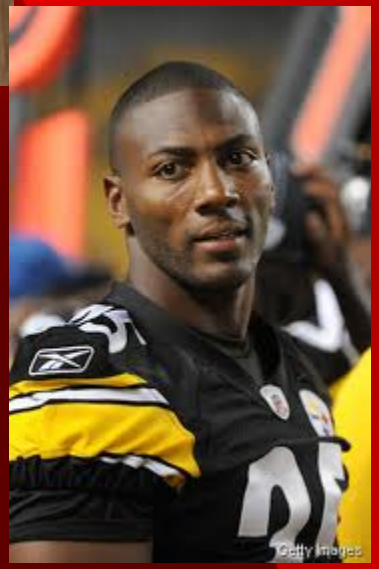
Over 1 million people are affected by Sickle Cell disease (5%).

SCA is commonly found in races originating from places such as:

Sub-Saharan Africa
Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America)
Saudi Arabia, India
Mediterranean countries such as Turkey, Greece, and Italy.

Who's Affected???

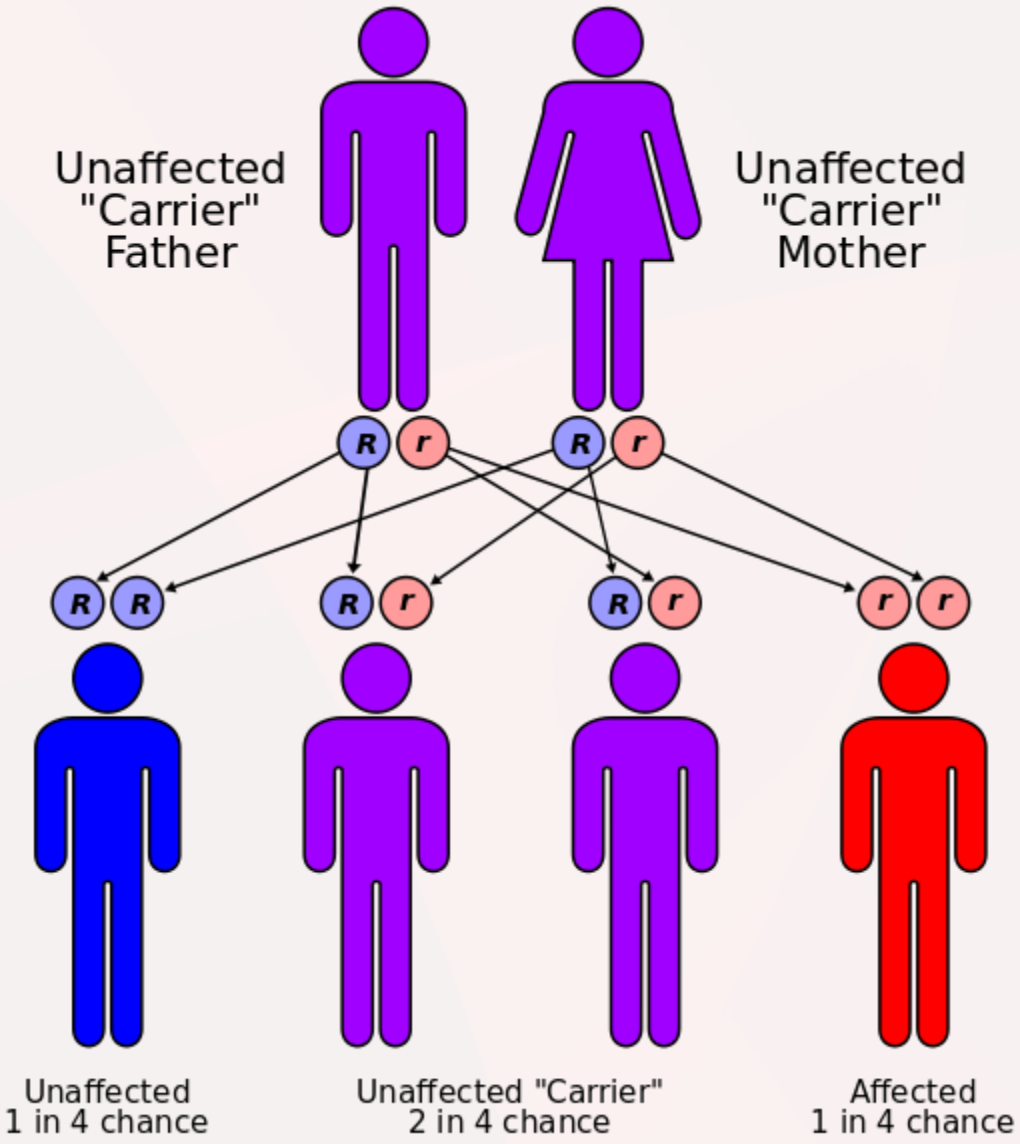




Genetics Behind SCA

The Sickle Cell gene is passed down through generations.

Sickle Cell is a hereditary disease.



Treatment (cont.)

Treatment and management of sickle cell includes:

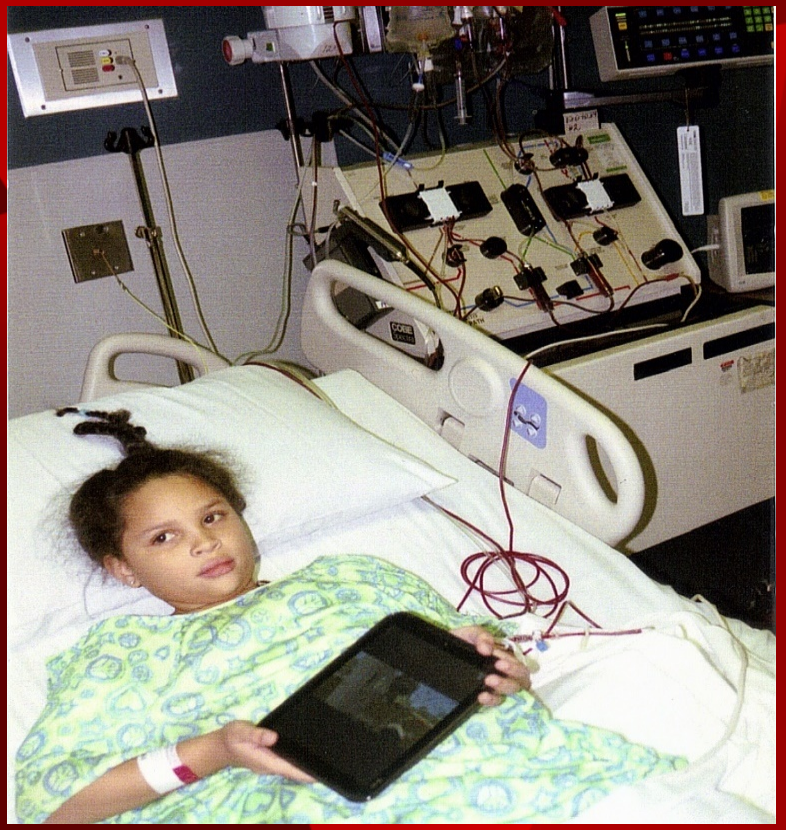
- ✓Folic acid supplements should be taken. Folic acid is needed to make red blood cells.
- ✓Blood transfusions (may also be given regularly to prevent stroke).
- ✓Blood Exchange and Transferrance
- ✓Pain medicines
- ✓Plenty of fluids

✓ Hydroxyurea (Hydrea), a medicine that may help reduce the number of pain episodes (including chest pain and difficulty breathing) in some people

Antibiotics to prevent bacterial infections, which are common in children with sickle cell disease

Transfusions

Blood Exchange



Our Purpose

The Sickle Cell Association of Kentuckiana's purpose is to provide sickle cell disease information, education, and client services within the State of Kentucky and the Louisville Metropolitan area. To develop and promote favorable resolutions of issues that impact individuals with sickle cell conditions in the State of Kentucky and the Louisville metropolitan area as well as maximizing the potential for public support of the organization.

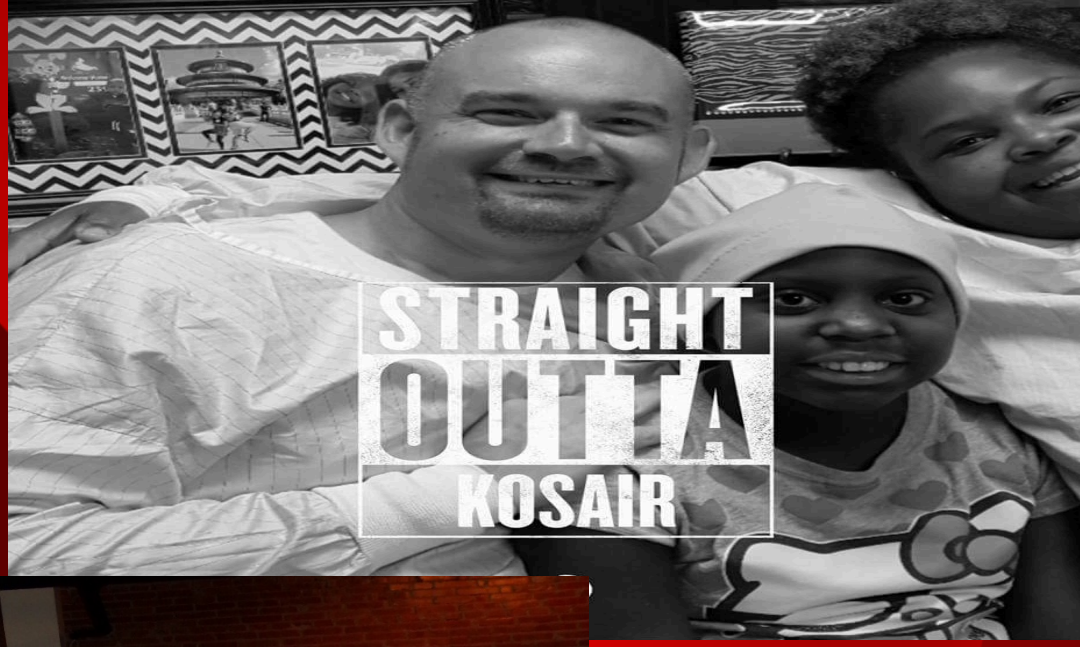
Cure or No Cure?

The only real cure for sickle cell is a bone marrow transplant. Sickle Cell is one of the oldest genetic diseases known to man.

Cure or No Cure? (cont.)

Doctors and researchers have been examining the potential of using Bone Marrow Transplants (BMT) to cure patients of the disease. Although some clinical trials has shown promising results for some patients who receive them, there is still work to be done.

BMT's are only an option if the patient has a viable bone marrow donor match.



APR. 7, 2004 EMILY BASS DEC. 2, 2017

What We Do…

The services provided by the Sickle Cell Association of Kentuckiana includes financial assistance with utility bills, medication co-pays, rent assistance, transportation costs to and from medical appointments/hospital visits locally and out of the area. Coordinate housing, food and transportation assistance between the sickle cell clinics, patients and family members seeking sickle cell treatment in the Louisville area. Advocate for passage of medication availability, treatments, and legislation at the State and Federal levels. Ensure students, parents and teachers are knowledgeable of the appropriate care plan provided by the Jefferson County School Board and when it should be implemented. On occasion, assistance with funeral costs.

How to help SCA patients…

✓Limit judgment (students can succeed)

✓Patients stay tired and/or fatigued

✓SCA patients typically miss many days of schooling due to crisis's, surgical operations, and other illnesses.

✓Extremely cold temperatures (classrooms, etc.) can bring about the onset of a pain crisis

✓Be flexible

What You Can Do…

- *Donate Blood*
  - Iron Overload
- *Donations*
  - Co-pays, Transportation, Utility Assistance
- *Educate Yourself*
  - Test yourself and know the outcome and consequences
- *Reach out*
  - Do you know someone with the disease and in need of help.

Contact Us

The Sickle Cell Association of Kentuckiana
201 East Jefferson Street Ste. 120
(Med 3 Center Building)
Louisville, KY 40202
Office: 502-569-2070
Email: thescak@yahoo.com
Website: www.thescak.org


WHO WIL
RUN FOR?
5K WALK & RUN
SICKLE CELL ASSOCIATION
OF KENTUCKIANA
"SICKLE CELL DISEASE, TRAIT CARRIERS AND SUPPORTERS"