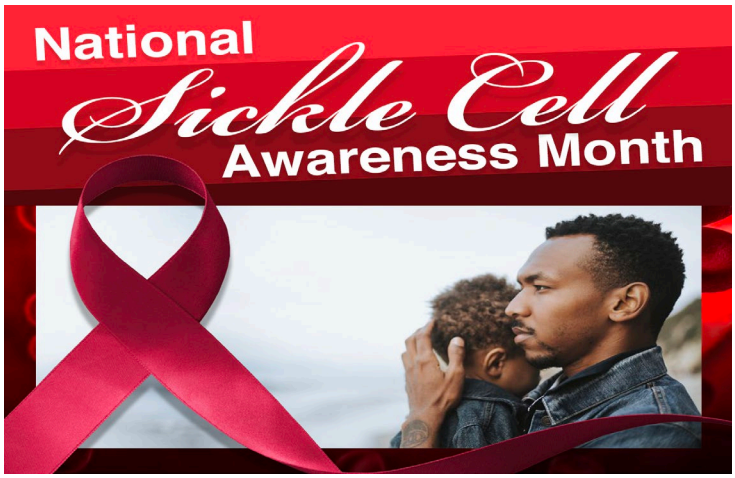

FROM THE SPAMEC HEALTH CONCERNS COMMITTEE

Sickle Cell Disease Awareness

September is National Sickle Cell Awareness Month. Sickle cell disease (SCD) is an inherited blood disorder in which red blood cells may become sickle-shaped and harden. For a baby to be born with sickle cell disease, both parents must carry a sickle cell trait or genes for another hemoglobin like HbC, HbE or beta thalassemia. Sickle cell disease is not contagious, and there is no universal cure.

We think about sickle cell as a Black disease, but it's not; it affects all sorts of nationalities. Sickle cell disease is a global health problem. The top countries for sickle cell disease in order of magnitude are Nigeria, India, Democratic Republic of Congo, and Tanzania. Outside the African continent, India has the largest concentration of patients with sickle cell disease. Worldwide there are about 300,000 babies born with sickle cell disease every year, and the majority in low-income countries will pass away before their fifth birthday.

Key Facts

- About 1 in 13 African Americans carry the sickle cell trait, and many do not know they have it.
- About 1 in every 365 Blacks have SCD
- Latinos have the second most common incidence in the U.S.
- About 1 in every 16,300 Hispanics have SCD
- An estimated 100,000 people in the U.S. have SCD.
- Approximately 2,000 babies are born with SCD annually in the U.S.
- On average, diagnosis is made at birth.

Symptoms and Complications

The blockage of blood flow caused by sickled cells leads to complications including:

- Chronic severe and unpredictable pain
- Anemia
- Frequent infections
- Swelling in extremities
- Fatigue
- Delayed growth
- Vision problems/blindness
- Lung tissue damage
- Kidney disease
- Stroke
- Shortened life expectancy
- Damage to hip joint

Staying Well

Get tested for sickle cell trait if you are of African descent and do not know your status. People with SCD can live full lives by being proactive in their care. Staying healthy with sickle cell disease involves:

- Pain management
- Preventing infections from common illnesses such as the flu
- Self-care including eating well, exercising and staying hydrated
- Medications to reduce the severity of sickle cell disease
- Regular preventive care including vaccinations and health and dental check ups
- Quality medical care from doctors and nurses who are educated about SCD
- Building a support system of friends and family
- Connecting with a patient support group or a community-based SCD organization for information and assistance

Treatment Options

• Over-the-counter pain relievers are commonly used to treat chronic pain.

• Hydroxyurea (Siklos, Droxia) and Oxbryta (Voxelotor) are prescribed medications that can decrease some complications of SCD.

• Endari (Glutamine) and Adakveo (Crizanlizumab) are prescribed medications that can reduce the number of sickle cell pain crises.

• Blood transfusions can help relieve symptoms of SCD and potentially prevent complications.

Screening Tests

• Newborn screening can help identify SCD and expedite early management and treatment.

• Adult screening can help identify if someone has SCD or is a carrier for the SCD trait.

• Sickle stroke screening, also known as Transcranial Doppler (TCD) screening, can help identify people with brain abnormalities as a result of SCD who are at high risk for ischemic stroke and brain injury.

• Organ screening can help identify damage to organs such as the kidney, eye and heart.

• Bone marrow (stem cell) transplants can, in some cases, cure sickle cell disease, but not all individuals are eligible for this procedure, and there are associated risks.