

OXIHER Health Priorities: Monthly Focus on Wellness

SEPTEMBER: Focus on Sickle Cell

Sickle Cell Awareness Month, observed every September, is dedicated to raising awareness about sickle cell disease (SCD) and its profound impact, particularly on the Black community. SCD is an inherited blood disorder that causes red blood cells to become rigid and shaped like a sickle. These sickle-shaped cells can block blood flow, leading to severe pain, organ damage and increased risk of infection.

Prevalence of Sickle Cell Disease

Sickle cell disease is most common among individuals of African descent. The [Centers for Disease Control reports](#) that an estimated one in 365 Black or African American births is affected by SCD, and one in 13 African American babies carries the sickle cell trait. "Because of this people falsely refer to SCD as a 'Black disease,' creating assumptions and stereotypes," says [Tammuella Singleton, MD](#), a member of the pediatric hematology team at Ochsner Medical Center - New Orleans. Dr. Singleton is a former director of the Sickle Cell Center of Southern Louisiana at Tulane University's School of Medicine. She currently serves as Chief Science Officer, American Hemostasis and Thrombosis Network.

Challenges Faced by Individuals with Sickle Cell Disease

Healthcare Disparities: Many individuals with SCD often face delayed diagnoses, inadequate treatment and a lack of access to specialized care, which is worsened by a shortage of physicians trained to provide evidence-based care. The systemic issues within the healthcare system can lead to worse health outcomes and a lower quality of life.

Lack of Resources in Rural Areas: Access to healthcare resources is often limited in rural areas, worsening the challenges faced by those with SCD. Rural patients may have to travel longer distances to receive specialized care, leading to delays in treatment and management of the disease.

Economic Strain: Managing SCD can be financially draining. Frequent hospital visits, costly medications, and the need for specialized care can strain families economically. Frequent episodes of severe pain can also make it harder to keep a steady job.

Undiagnosed or Misdiagnosed Conditions: Many patients are born with sickle cell disease, but it often goes undiagnosed or misdiagnosed until much later in life. This delay in diagnosis can lead to a lack of early intervention and management, worsening the patient's prognosis and quality of life.

Psychosocial Impact: Living with a chronic illness like SCD can take a toll on mental health. The constant battle with pain, frequent hospitalizations and the stigma associated with the disease can lead to feelings of isolation, anxiety, and depression.



The Painful and Debilitating Nature of Sickle Cell Disease

Sickle cell disease is not only extremely painful but also debilitating and potentially deadly. The sickle-shaped cells can cause blockages in blood vessels, leading to episodes of severe pain known as sickle cell crises. These crises can result in complications such as stroke, [acute chest syndrome](#) and organ damage. The disease significantly shortens life expectancy and diminishes the quality of life for many patients.

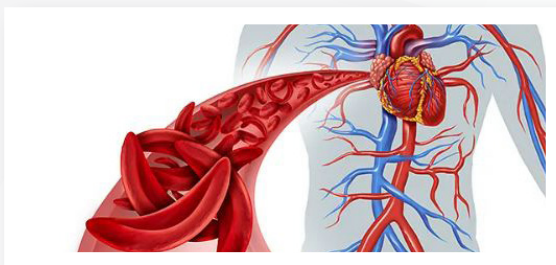
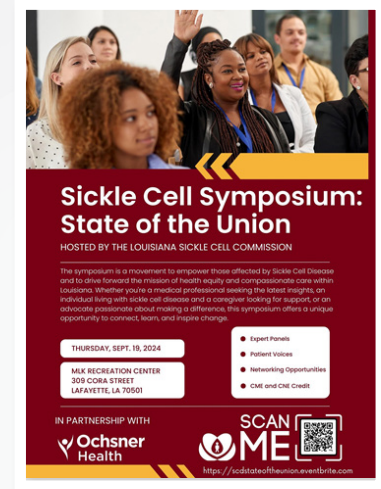
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Importance of Awareness and Support

Raising awareness about sickle cell disease is vital for several reasons. Educating the public reduces stigma and promotes early detection through newborn screening programs. Awareness initiatives also highlight the need for better healthcare policies and funding for research aimed at finding a cure.

How to Get Involved

- **Educate Yourself and Others:** Knowledge is power. Learn about SCD and share information within your community to dispel myths and foster understanding.
 - **Sickle Cell Symposium:** The Louisiana Sickle Cell Commission will host this event on September 19, 2024, in Lafayette in association with Ochsner. It is offered at no cost to physicians, APPs, nurses, patients, their loved ones, and members of the public interested in SCD. Advance registration is required. CME and CNE credit is available. The CME Program Director is [Raj Warriar, MD](#), Ochsner Children's Hospital.
 - **Ochsner's "To Your Health" blog** offers insights on [SCD and its impact on newborns](#)
- **Participate in Awareness Campaigns:** Engaging in local and national Sickle Cell Awareness Month events can help amplify the message. From walks and fundraisers to social media campaigns, every effort counts.
- **Consider Donating Blood and Bone Marrow**
 - Persons with SCD may need as many as [100 units of blood per year](#). Donations to [Ochsner's Blood Bank](#) and other blood donation organizations help alleviate the pain and suffering of SCD patients.
 - [The only known cure for SCD is BMT](#) or bone marrow transplant. The [Be the Match](#) organization matches patients with donors.



Sickle Cell Awareness Month serves as an important reminder of the ongoing battle against sickle cell disease, particularly within the Black community.

By shedding light on the prevalence, challenges and need for awareness, we can collectively work towards a future where those affected by SCD have access to the care and support they need.

Through education, advocacy, and support, we can make a significant impact in the lives of many and move closer to finding a cure for this debilitating disease.