Supporters of Families with Sickle Cell Disease, Inc. Oklahoma Sickle Cell

6/20/2023

Supporters of Families with Sickle Cell Disease, Inc.

Founded in 2004, SFSCD is the only nonprofit organization (501c3) in Oklahoma dedicated to exclusively serving families living with sickle cell disease (SCD). We are committed to increasing knowledge, awareness, advocacy and support for people living with chronic health conditions of sickle cell disease in Oklahoma and highlighting the challenges and impact to individuals, families and communities living with these diseases.

Supporters of Families with Sickle Cell Disease, Inc.

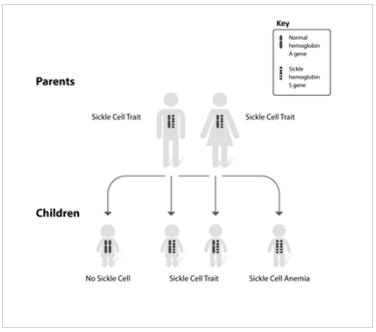
Mission

Our mission is to improve the quality of life for children, adults, and their families who live with sickle cell and thalassemia within Oklahoma through systematic changes in patient care, policy, education, advocacy, family support, economic, self-sufficiency, and awareness.

SCD is a group of inherited red blood cell disorders. Healthy red blood cells are round, and they move through small blood vessels to carry oxygen to all parts of the body. In someone who has SCD, the red blood cells become hard and sticky and look like a C-shaped farm tool called a "sickle".

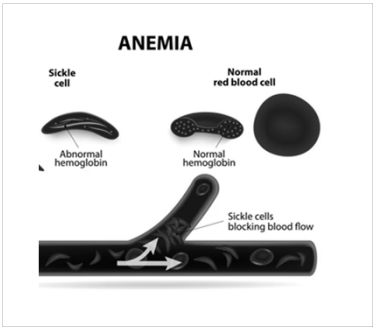
The sickle cells die early, which causes a constant shortage of red blood cells. Also, when they travel through small blood vessels, they get stuck and clog the blood flow. This can cause pain and other serious problems such infection, acute chest syndrome and stroke

What is SICKLE CELL DISEASE?



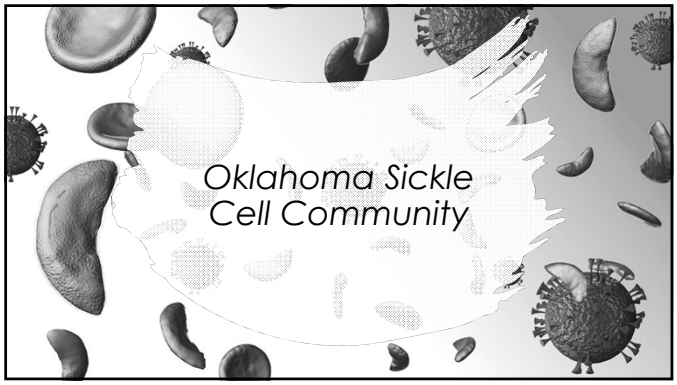
- If both parents have SCT, there is a 50% (or 1 in 2) chance that any child of theirs also will have SCT, if the child inherits the sickle cell gene from one of the parents. Such children will not have symptoms of SCD, but they can pass SCT on to their children.
- If both parents have SCT, there is a 25% (or 1 in 4) chance that any child of theirs will have SCD. There is the same 25% (or 1 in 4) chance that the child will not have SCD or SCT.

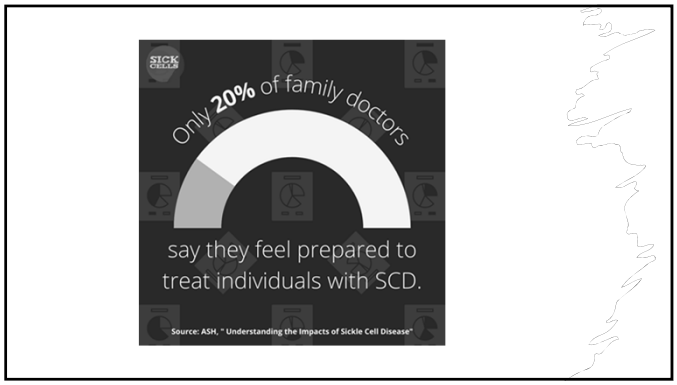
What is SICKLE CELL TRAIT?

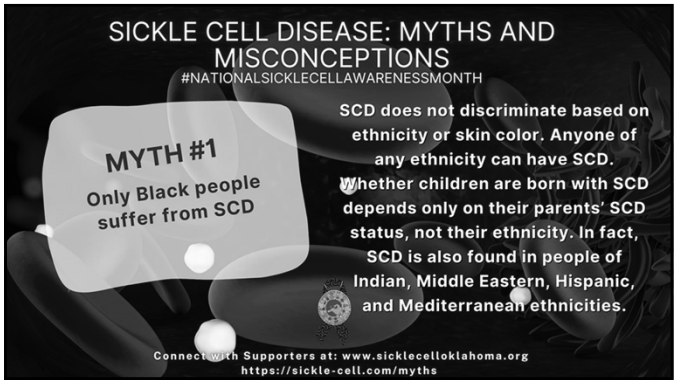


Sickle Cell Disease and Sickle Cell Trait

- SCD affects approximately 100,000 Americans.
- SCD occurs among about 1 out of every 365 Black or African-American births.
- SCD occurs among about 1 out of every 16,300 Hispanic-American births.
- About 1 in 13 Black or African-American babies is born with sickle cell trait (SCT).


Oklahoma Sickle Cell Community


SICK CELL
Only 20% of family doctors
say they feel prepared to treat individuals with SCD.
Source: ASH, " Understanding the Impacts of Sickle Cell Disease"


SICKLE CELL DISEASE: MYTHS AND MISCONCEPTIONS
#NATIONALSICKLECELLAWARENESSMONTH
MYTH #1
Only Black people suffer from SCD
SCD does not discriminate based on ethnicity or skin color. Anyone of any ethnicity can have SCD. Whether children are born with SCD depends only on their parents' SCD status, not their ethnicity. In fact, SCD is also found in people of Indian, Middle Eastern, Hispanic, and Mediterranean ethnicities.
Connect with Supporters at: www.sicklecelloklahoma.org
https://sickle-cell.com/myths

Sickle Cell Race & Ethnicity Population Distribution

	Sickle Cell Disease (SCD)		Sickle Cell - Other Hemoglobinopathy		Thalessemia		Sickle Cell Trait (SCT)		Total All DXs	
RACE	**Count**	**% 972**	**Count**	**% 1066**	**Count**	**% 1841**	**Count**	**% 2636**	**Count**	**% 6515**
African American/Black	737	75.8%	256	24.0%	720	39.1%	1751	66.4%	3464	53.2%
Am. Indian/Alaskan Native	23	2.4%	54	5.1%	92	5.0%	117	4.4%	286	4.4%
Asian/Pacific. Is./Hawaiian	3	0.3%	30	2.8%	130	7.1%	11	0.4%	174	3%
Multiracial (+1 w/o Dx)	57	5.9%	105	9.8%	125	6.8%	330	12.5%	617	9.5%
Caucasian/White	108	11.1%	579	54.3%	683	37.1%	293	11.1%	1663	25.5%
Declined	44	4.5%	42	3.9%	91	4.9%	134	5.1%	311	5%
TOTAL	**972**	100.0%	**1066**	100.0%	**1841**	100.0%	**2636**	100.0%	**6515**	100.0%
ETHNICITY										
Hispanic	46	4.7%	134	12.6%	235	12.8%	243	9.2%	658	10.1%
Not-Hispanic	926	95.3%	932	87.4%	1606	87.2%	2393	90.8%	5857	89.9%
TOTAL	**972**	100.0%	**1066**	100.0%	**1841**	100.0%	**2636**	100.0%	6515	100%

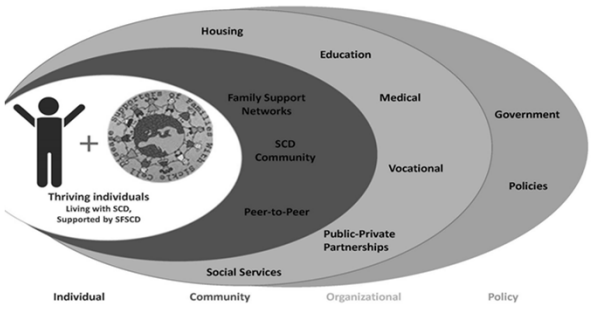
The Program grantees, and federally qualified community health centers address structural and systemic barriers in their regions, implement evidence-based SCD care, and collaborate with newborn screening programs so that every infant identified with SCD gets early and prompt care.

SCD HRSA NEWBORN SCRENING **PROGRAM**

SCD HRSA NEWBORN SCREENING PROGRAM

There are still barriers to accessing comprehensive, high-quality care throughout a person's lifespan.

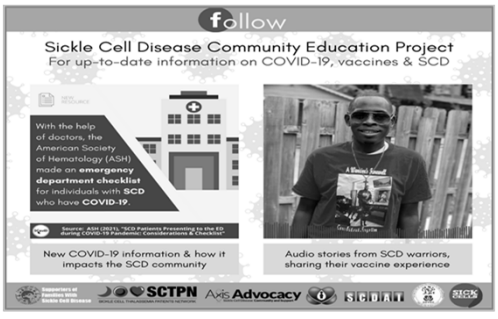
- Some of these barriers include a lack of access to evidence-based care,
- A lack of access to disease modifying medications and therapies
- Inadequate workforce training and education
- The need for a high degree of multi-disciplinary care coordination from infancy to adulthood.



COVID-19 and Vaccine Basics

Why should the sickle cell community be especially concerned?

- People with sickle cell disease are at a high risk for severe COVID-19 complications because of the common issues shared by the two conditions.
- SCD and COVID-19 can both cause increased blood clotting, damage to blood vessels and lung problems. SCD patients are also at a higher risk for acute chest syndrome.
- The case fatality rate for people with SCD who get COVID-19 is almost double the case fatality rate for the general US population.



Welcome to SECURE-SCD

Secure-SCD Registry, Surveillance Epidemiology of Coronavirus (COVID-19) Under Research Exclusion Overview

This registry is designed to capture pediatric and adult COVID-19 cases that are occurring across the world in patients living with sickle cell disease. The goal of the registry is to report on outcomes of cases of COVID-19 in this population of patients. We are asking providers caring for these patients to report all of their cases of COVID-19 to this registry. We expect the reporting of a case to take approximately 5-10 minutes.

Please report only confirmed COVID-19 cases, and report after sufficient time has passed to observe the disease course through resolution of acute illness and/or death.

- https://covidsicklecell.org/

Supporters of Families with Sickle Disease

Better Together- Partnerships

A **system of care coordination** will be developed to facilitate the delivery of integrated health and supportive services to better manage SCD, related hemoglobinopathies and Covid-19.

A template for a proactive plan of care will be created to respond to the current and anticipated needs of clients, including Covid-19 special care.

Increase self-care management, provider and client education, increase health and resource navigation

Goals for care will be set and coordination gaps will be addressed to **link clients to local, regional, and state-based community resources**.

Contact Information

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