

Sickle Cell Disease (SCD) Community Based Support Program

Provided by CareStar Inc.

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Health

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What is Sickle Cell Disease?

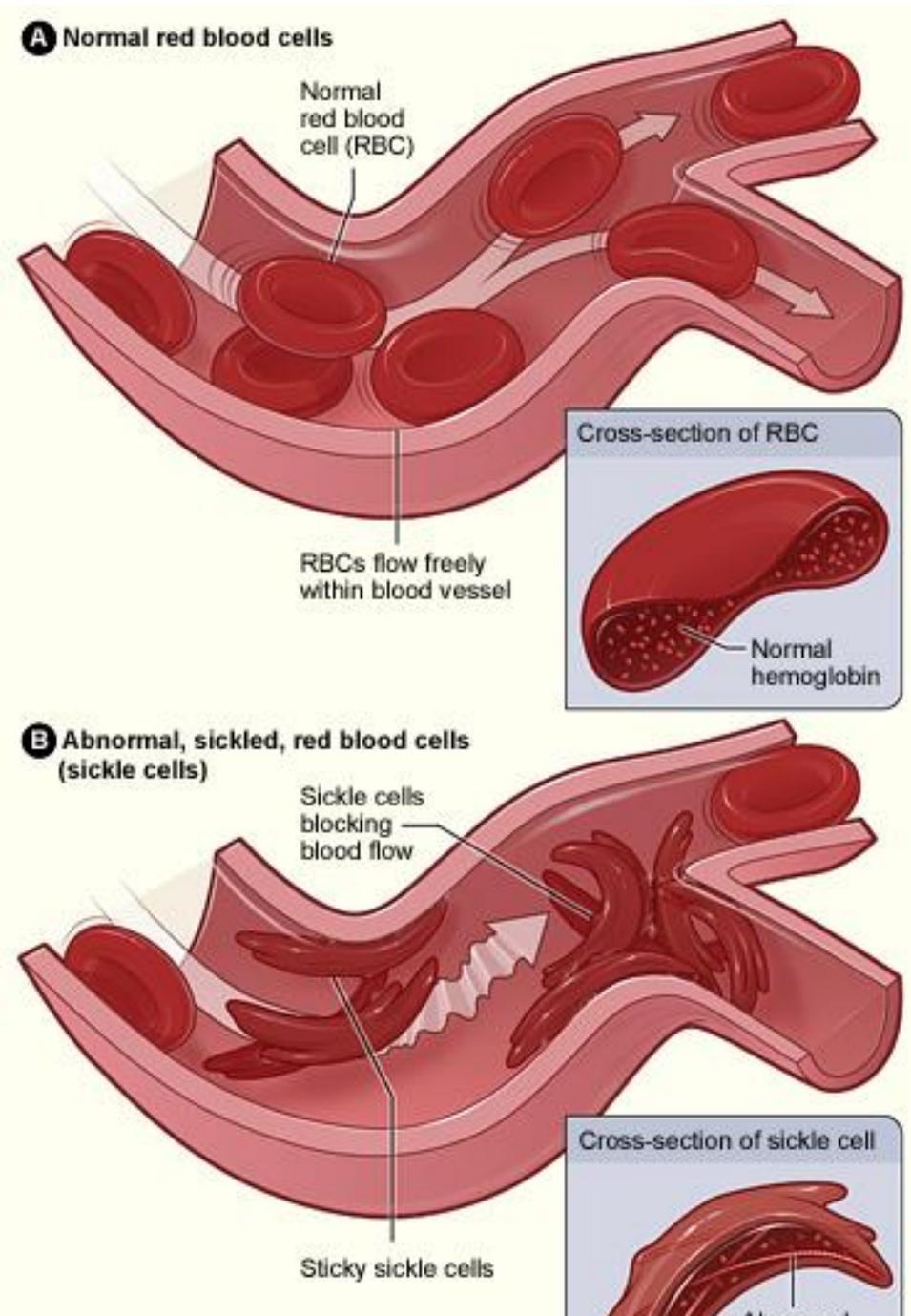
Sickle cell disease (SCD) is a group of inherited red blood cell disorders.

Healthy red blood cells are round and they move through small blood vessels carrying oxygen to all parts of the body.

For someone with SCD, the red blood cells become hard and sticky and look like a C-shaped farm tool called a "sickle".

Sickle cells die early in comparison to non-sickle cells, which causes a constant shortage of red blood cells.

Sickle cells can get stuck in small blood vessels and block the flow of blood and oxygen to organs in the body. These changes in cells can cause repeated episodes of severe pain, organ damage, serious infections, or even stroke.



What causes SCD?

- ❖ SCD is inherited in the same way that people get the color of their eyes, skin, and hair.
- ❖ A person with SCD is born with it.
- ❖ People cannot “Catch” SCD from being around a person who has it.



Who is affected?

- ❖ It is estimated that SCD affects 90,000 to 100,000 people in the United States, mainly Blacks or African Americans.
- ❖ The disease occurs among about 1 of every 365 Black or African-American births and among about 1 of every 16,300 Hispanic-American births.
- ❖ 1 in 13 Black or African-American babies is born with sickle cell trait (SCT).
- ❖ SCD affects approximately 3,890 individuals statewide (Pennsylvania)

What Health Problems Does Sickle Cell Disease Cause?

Most common complications of SCD:

Pain Episodes or Crises—Sickle cells do not move easily through small blood vessels and can get stuck and clog blood flow. This causes pain that can start suddenly and be mild to severe

Infection—People with SCD, especially infants and children, are more likely to experience harmful infections such as influenza, meningitis (infection of the brain or spinal cord)

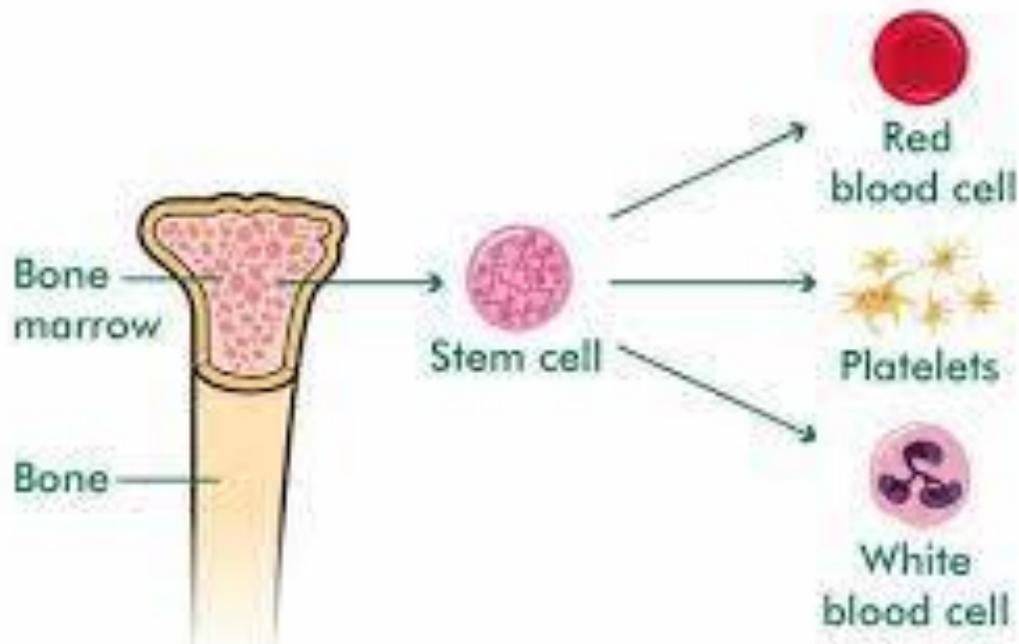
Hand–Foot Syndrome—Swelling in the hands and feet

Eye Disease—SCD can affect the blood vessels in the eye and lead to long-term damage.

Acute Chest Syndrome (ACS)—Blockage of the flow of blood to the lungs can cause acute chest syndrome

Cerebral Infarction (Stroke)

Is There a Cure for Sickle Cell Disease?



- To date, the only cure for SCD is a bone marrow or stem cell transplant.
- A bone marrow or stem cell transplant is a procedure that takes healthy stem cells from a donor and puts them into someone whose bone marrow is not working properly. These healthy stem cells cause the bone marrow to make new, healthy cells.
- Bone marrow or stem cell transplants are very risky, and can have serious side effects, including death. For the transplant to work, the bone marrow must be a close match.

How Is Sickle Cell Disease Treated?

The goals of treating SCD are to relieve pain, prevent infections, eye damage, and strokes.

There is no single best treatment for all people with SCD. Treatment options are different for each person depending on the symptoms. Treatments can include receiving blood transfusions, receiving intravenous therapy (fluids given into a vein), and medications to help with pain.

For severe SCD, a medicine called hydroxyurea might be recommended. Research suggests that hydroxyurea can reduce the number of painful episodes and the recurrence of Acute Chest Syndrome. It also can reduce hospital stays and the need for blood transfusions among adults who have SCD.

Six Steps to Living Well With Sickle Cell Disease

01

Find effective medical care

02

Participate in regular check ups

03

Prevent infections

04

Learn healthy habits

05

Research clinic studies

06

Create a support network



Getting Support from
CareStar's Sickle Cell Disease
(SCD) Community Based
Support Program



CareStar®

Improving Communities by Improving Lives

Who are we?

CareStar has 33 years of experience serving pediatric to geriatric populations with chronic health needs, complex health conditions and disabilities, and partnering with clients through community health work to assist families navigating their way through what can be a complex health care system. CareStar is a provider of patient-focused case management which is proud to report having over a 95% patient satisfaction rating throughout all deliverable programs.

What Do We Do?

The SCD program is designed to improve health outcomes to those diagnosed with Sickle disease and/or those who carry the trait. The goal of the program is designed to enhance communication and service provision between the client and health care systems, enhance equitable access to services, support client integration into the community, and educate the community on the needs of those with sickle cell disease.

Additionally, CareStar provides Education, Advocacy, and Support so members can live healthy, productive and self-sufficient lives.



We provide community health work via Community Health Workers (CHW). The CHW work 1:1 with individuals, providing needed services requested by the individual. The CHW will meet with the individual at their home or in the community.

Services Offered

Individualized goal planning with supportive coaching.

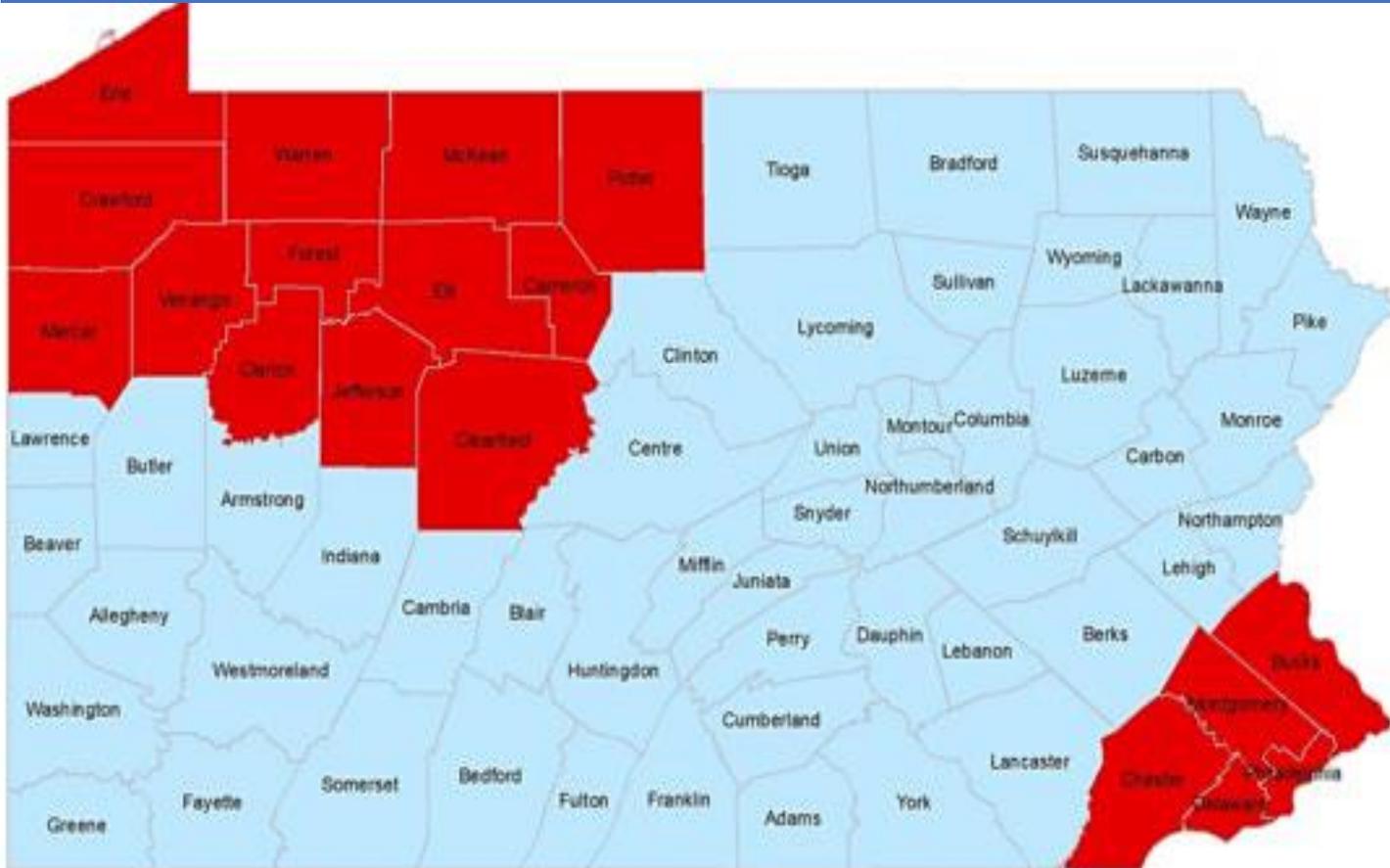


The CHW will schedule a face-to-face meeting with individual, based on their choosing to evaluate needs and solutions to address gaps or barriers in service delivery.



Care planning that includes the development, implementation and support associated with the creation of a unified care plan that supports you through your lifespan.

Who/Where do we serve?



We serve the Southeast Regions of Pennsylvania: Bucks, Chester, Delaware, Montgomery and Philadelphia.

Northwest Regions of the state: Potter, Clarion, Cameron, Crawford, Clearfield, Elk, Erie, Forest, Jefferson, McKean, Mercer, Venango, and Warren counties.

How does it work?

An individual is either referred from an establishment or is self referred.

Once an individual is accepted into the SCD program, they will be assigned a CHW.

The CHW will complete an assessment and create a unified care plan with specific tasks and action steps to complete each goal created.

The CHW will provide a partnership to include but not limited to, aiding individuals in attendance to appointments, roadmaps to self-sufficiency, family interaction, medical care navigation, and mental health support.

Examples of Resources include but not limited to:

COMMUNITY CONNECTIONS NEEDED (Please check all that apply).

Developing S.M.A.R.T GOALS	<input type="checkbox"/>	Insurance Information Sheet	<input type="checkbox"/>	Daily Pain Tracking Sheet	<input type="checkbox"/>
Healthy Behavior Contract	<input type="checkbox"/>	Transfusion Tracking Sheet	<input type="checkbox"/>	Describe the Pain Sheet	<input type="checkbox"/>
Six Steps to Living Well With Sickle Cell Disease	<input type="checkbox"/>	Specialist	<input type="checkbox"/>	Stress Diary Sheet	<input type="checkbox"/>
Five Tips to Help Prevent Infections	<input type="checkbox"/>	Medical Supplies	<input type="checkbox"/>	Budgeting	<input type="checkbox"/>
Emergency Guide: When to See the Doctor	<input type="checkbox"/>	Home Health Care	<input type="checkbox"/>	Bill Paying	<input type="checkbox"/>
Coping With Stress	<input type="checkbox"/>	Medication Log Sheet	<input type="checkbox"/>	Daily Physical Activity Tracking Sheet	<input type="checkbox"/>
Fifteen Reasons Why Exercise Is Good	<input type="checkbox"/>	Vaccination and Immunization Tracking Sheet	<input type="checkbox"/>	Water Intake Tracking Sheet	<input type="checkbox"/>
Medical Appointment Sheet	<input type="checkbox"/>	. Hospitalization and Surgical Procedures Tracking Sheet	<input type="checkbox"/>	Misc. Community Resources	<input type="checkbox"/>
Pharmacy Provider Information Sheet	<input type="checkbox"/>	Health Education	<input type="checkbox"/>	Other:	<input type="checkbox"/>

An illustration of various hands and forearms raised against a bright yellow background. The hands are rendered in different colors and styles, including solid colors, outlines, and patterns like stripes and polka dots. The arms are raised at different heights and angles, creating a sense of movement and diversity. A white horizontal band with a thin black border runs across the middle of the image, containing the text.

Any Questions?

Reference Page

- **SSI Kids Toolkit**
 - <https://www.ssa.gov/thirdparty/materials/pdfs/SSI%20Kids%20Toolkit.pdf>
- **CareStar's SCD Marketing Flyer, June 2021**
- **CareStar's SCD Referral Form, June 2021**
- **Centers for Disease Control and Prevention (CDC)**
 - <https://www.cdc.gov/ncbddd/sicklecell/data.html>
- **Prevalence of Sickle Cell Disease among Medicaid Beneficiaries (U.S. Dept. of Health and Human Services), June 2019**
 - <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Data-Highlight-16-Sickle-Cell-Disease.pdf>
- **SCD Image**
 - https://www.google.com/search?q=sickle+cell+disease&rlz=1C1GCEU_enUS917US918&sxsrf=AOaemvLnrttd1cVj-m4B99sGRlgvngYCvw:1630430956066&source=lnms&tbm=isch&sa=X&ved=2ahUKewjU2N3P5NvyAhXHGs0KHeE0CxMQ_AUoAnoEC_AEQBA&biw=1280&bih=616#imgrc=2T_y9ikXpAqn1M
- **Bone marrow or stem cell transplant Image**
 - <https://www.macmillan.org.uk/cancer-information-and-support/treatment/types-of-treatment/stem-cell-and-bone-marrow-transplants/stem-cells-and-bone-marrow>