ROSWELL PARK COMPREHENSIVE CANCER CENTER

SICKLE CELL TRAIT & DISEASE *Info Sheet*

WHO GETS SICKLE CELL DISEASE?

As genetic and inherited conditions, sickle cell trait and disease most commonly affect people of **African heritage**. However, the conditions are found in these groups, too:

- ✔ African-American
- ✔ Latino/Hispanic
- ✔ Middle Eastern
- ✔ Indian/South Asian
- ✔ African-Caribbean
- ✔ Southern European (Italian, Greek)

1 in 13 **African-Americans** & **1 in 100** **Latino/Hispanic** persons have **sickle cell trait**

WHAT IF I HAVE SICKLE CELL DISEASE?

You are not alone. Learning about your condition and seeing your sickle cell disease physician regularly can help identify, reduce and prevent some complications. In addition, you should:

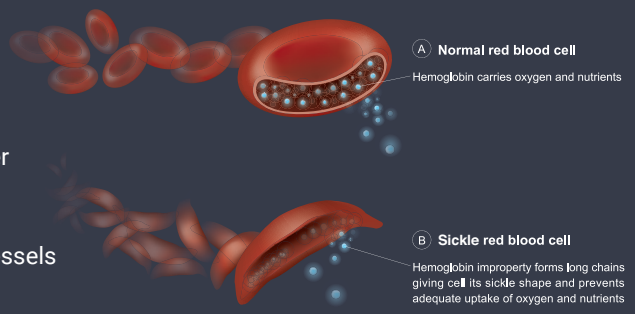
- ✔ Stay well hydrated
- ✔ Avoid cold exposure
- ✔ Eat a healthy diet
- ✔ Learn your risk for having a child with sickle cell trait or disease
- ✔ Seek support from family, friends and your medical team

WHAT YOU SHOULD KNOW

Sickle cell disease is a blood disorder that affects the **red blood cells**. Healthy red blood cells are round and flexible and move easily through blood vessels. They contain a protein called hemoglobin that allows them to carry oxygen throughout the body.

Sickle cell disease occurs when the hemoglobin is abnormal (called *Hemoglobin S),* making the red blood cells rigid, sticky and shaped like a banana or sickle. These sickle-shaped red blood cells can:

- ✔ Clump together
- ✔ Block blood flow
- ✔ Break down faster than healthy cells
- ✔ Damage blood vessels



WHAT PROBLEMS DOES SICKLE CELL DISEASE CAUSE?

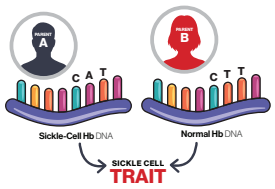
Sickle cell disease can range from mild to very severe. Because it affects the blood, it can lead to complications throughout the body, including:

- **Anemia**, or low number of red blood cells in your blood, possibly causing fatigue, decreased activity tolerance, headaches and shortness of breath.
- **Pain** from sickle cells blocking blood flow to muscles, bones and other body areas. The pain can range from mild to severe and occur in episodes, called pain crises, or become chronic.
- **Jaundice** or yellowing of the eyes and skin.
- **Infection of the blood,** or sepsis, which can be deadly without prompt treatment.
- **Lung damage**, or acute chest syndrome, caused when sickle cells block blood flow in the lungs.
- **Stroke** caused when sickle cells damage the blood vessels in the brain.
- **Organ damage**. Almost any organ in the body can be affected.
- **Pregnancy complications**. Women with sickle cell disease are more likely to experience complications during pregnancy.

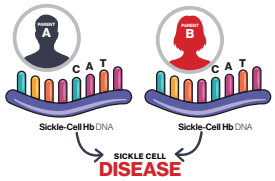
SICKLE CELL DISORDERS ARE GENETIC

Sickle cell disease is caused by inheriting faulty hemoglobin genes from your parents. You are born with it. You cannot develop it later in life and it is not contagious. Everyone inherits two copies of the beta-globin gene for hemoglobin, one from each parent. If one or both of your parents carry the abnormal *hemoglobin S* gene, the following can occur:

THE RISK FOR SICKLE CELL DISEASE IS HIGHER IF ONE PARENT ACTUALLY HAS SICKLE CELL DISEASE.



Sickle cell trait occurs when only **ONE** of your two hemoglobin genes is abnormal.



Sickle cell disease happens when **BOTH** your hemoglobin genes are abnormal.

YOU MAY INHERIT TWO ABNORMAL GENES IF:

- Both parents have sickle cell trait
- One parent has sickle cell trait and the other has another abnormal hemoglobin gene, like beta-thalassemia trait or hemoglobin C trait.

WHAT IF I HAVE SICKLE CELL TRAIT?

Sickle cell trait does not develop into sickle cell disease, but can increase the risk for:

- Rare complications, muscle damage or even sudden death, especially in situations like high altitude or extreme physical exertion
- Kidney damage and kidney cancer
- Having a child with sickle cell disease

HOW WE CAN HELP

The **Sickle Cell & Hemoglobinopathy Center of WNY** is the referral center for all newborns in Western and Central New York with sickle cell disease and other hemoglobin disorders. Our center provides:

- Experts in sickle cell disease and other childhood blood disorders
- Medical and support team for children with sickle cell disease, including nurse practitioner, nurses, patient navigator, psychologists, social worker, and other ancillary staff
- Bone marrow transplant options
- Pediatric infusion suite at Roswell Park and inpatient care at Oishei Children's Hospital

> "As a sickle cell disease warrior, I believe that positivity and a strong support system are two of the most important factors when living with this disease. It can be the key to a longer and healthier life."
>
> **- Juanita McClain,** sickle cell patient

HOW IS SICKLE CELL DISEASE TREATED?

Treatments to improve the disease, reduce symptoms or prevent complications include:

- **Drugs** such as hydroxyurea, voxelotor, crizanlizumab, and L-glutamine
- **Chronic blood transfusions**
- **Folic acid**, a vitamin
- **Penicillin** to prevent life-threatening blood infections in children
- **Bone marrow transplant** and recently approved **gene therapy** are the only potential cures for sickle cell disease

MEET OUR TEAM

Steven Ambrusko, MD, MS
Pediatric Hematology/Oncology
Director of Sickle Cell & Hemoglobinopathy Center of WNY

Katie Carlberg, MD
Pediatric Hematology/Oncology

Taylor Kochanski, MS-FNP
Nurse Practitioner

Taryn Saracina, PhD
Medical Psychologist
Non-Malignant Hematology

ROSWELL PARK | OISHEI Children's

CANCER AND BLOOD DISORDERS PROGRAM

UB|MD PEDIATRICS

SICKLE CELL & HEMOGLOBINOPATHY CENTER OF WNY
At Roswell Park/Oishei Children's Cancer & Blood Disorder Program
Elm & Carlton Streets | Buffalo, NY 14263 | 716-845-4447 | RoswellPark.org/blood-disorders

53331 (07/24)