



Facts about **Sickle Cell** Disease for Teachers, Coaches and School Nurses

Sickle cell disease (SCD) is the term used to describe a **group of inherited blood disorders** that affects the hemoglobin component of the red blood cells. Hemoglobin is a protein that carries oxygen from the lungs to different parts of the body. The most common types of SCD are hemoglobin SS disease (also called sickle cell anemia), hemoglobin SC disease and two types of sickle beta (β)-thalassemia syndromes (S β^+ -thalassemia and S β^0 -thalassemia).

This document is intended to serve as a quick reference guide for teachers, coaches and school nurses on the everyday needs of the student with SCD. It is not intended to be inclusive of all situations encountered in the school setting. A selected resource listing is provided on the reverse for detailed information regarding the signs and symptoms of complications and the medical management of the school-aged student with SCD.

*All students with a **diagnosis of SCD** should have a current, individualized health care plan on file each school year.*

Everyday needs of the student with sickle cell disease

- ▼ **Give lots of fluids.** Make sure your student has fluids readily available at all times in class. Encourage frequent trips to the water fountain or allow the student to keep a water bottle at his/her desk and during physical education/activity. Fluids assist the red blood cells in moving more easily through the blood vessels, which ultimately decreases the number of pain episodes your student may experience.
- ▼ **Provide liberal bathroom privileges.** Due to their high fluid intake and because their kidneys do not function as well as healthy children, allow your student with SCD non-disruptive, unlimited access to the restroom. This includes providing a permanent bathroom pass and classroom seating in close proximity to an exit so the student can leave as often as necessary to use the restroom.
- ▼ **Avoid physical exhaustion.** Because of the anemia characteristic of this disease, students with SCD may tire more easily than other children.

Allow your student time to rest when needed. Inclusion in most activities without restrictions is encouraged. If in doubt about the student's participation in certain activities, confer with the parents/caregivers and health care provider (with parental permission).

- ▼ **Avoid extreme temperatures.** Temperature extremes can trigger a pain episode. Students should not be exposed to temperature extremes of less than 45 degrees and greater than 80 degrees for long periods of time. In hot weather, your student may need more frequent breaks for rest and water or juices to avoid dehydration. In cold weather, layered clothing, including boots and hats should be worn during outside emergency drills. Temperatures in the classroom must also be moderately regulated. Classrooms that are too cold or too hot may cause increased red blood cell sickling and precipitate a pain episode.

Common medical complications of sickle cell disease

- ▼ **Pain.** Pain is the most common problem in sickle cell disease. A pain episode (commonly called a "crisis") may occur at any time (either gradually or suddenly), with or without physical or psychological stress and in any part of the body. Each student will differ in terms of severity, duration and frequency of pain. Follow the pain relief instructions/plan as directed by the student's parents/caregivers and health care provider.
- ▼ **Acute Chest Syndrome. This is a medical emergency.** It is believed to be caused by sickled red blood cells clogging blood vessels in the lungs. Sometimes, acute chest syndrome is caused by pneumonia or can lead to pneumonia. **If your student experiences any of the symptoms listed below, contact the parents/caregivers immediately:**
 - Fever greater than 101 degrees
 - Chest pain
 - Congestion
 - Cough
 - Trouble breathing or shortness of breath
 - Rapid breathing

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- ▼ **Anemia.** Normal red blood cells live for approximately 90 to 120 days before they break down. Sickled red blood cells live only 10 to 20 days. As the body is unable to produce sufficient red blood cells for replacement, the result is anemia. Some symptoms of anemia are:
- Tiredness or decreased energy
 - Weakness
 - Paleness/pallor
 - Headache
- ▼ **Infection.** Fever or temperature greater than 101 degrees, is often the first sign of infection (***infection is a life-threatening problem in sickle cell disease***). Children with SCD are not able to fight infection and need to receive IV antibiotics. **Contact the parents/caregivers immediately.** Do not give acetaminophen or ibuprofen so as not to mask the fever.
- ▼ **Stroke.** Sickled cells can block the blood vessels in the brain and keep the brain from getting enough oxygen. About 12 percent of children with SCD have a stroke by age 18, with the average age between 4 and 6 years old. Cognitive changes in the student's attention or school performance, no matter how subtle, should be discussed with the parents/ caregivers right away. **If you notice any of the following, call 911 and the student's parents/caregiver immediately:**
- Weakness or loss of feeling
 - Confusion
 - Difficulty swallowing
 - Unsteady walk
 - Inability to move on side of face or arms/legs (paralysis)
 - Seizure or loss of consciousness
 - Slurred speech
 - Severe headache
- ▼ **Jaundice.** Jaundice or yellow coloring of the eyes or skin, is caused by bilirubin, a byproduct of red blood cell destruction. Because sickled red blood cells are destroyed more rapidly than normal cells, there is an increased amount of bilirubin. Be mindful of teasing by other students. Many children with jaundice develop problems with self-esteem and/or self-image. The school psychologist may be helpful. Discuss with parents/caregivers.

Education Plans

Education plans, such as Section 504 or Individualized Education Program (IEP), explain what medical accommodations, educational aides and services the student with SCD may need in the school setting. A "504 Plan" is the commonly used term for a plan of services developed under Section 504 of the Rehabilitation Act of 1973 to ensure the child with a disability has equal access to education. An IEP is required for students who receive special education and related services under the Individuals with Disabilities Education Act. A reassessment of the content specific to either a Section 504 or IEP is recommended each school year.

For More Information

Region I

Comprehensive Sickle Cell Center
Cincinnati Children's Hospital Medical Center
3333 Burnet Avenue, MLC 7015
Cincinnati, Ohio 45229
(513) 636-7541

Region II

West Central Ohio Comprehensive
Sickle Cell Center
Dayton Children's Medical Center
One Children's Plaza
Dayton, Ohio 45404
(937) 641-5014

Region III

Sickle Cell Project of Northwest Ohio
Cordelia Martin Health Center
430 Nebraska Avenue
Toledo, Ohio 43604
(419) 255-7883 ext. 110

Region IV

Comprehensive Sickle Cell Disease and
Thalassemia Program
Nationwide Children's
700 Children's Drive
Columbus, Ohio 43205
(614) 722-5948

Region V

American Sickle Cell Anemia Association
10900 Carnegie Avenue
DD Building, Suite DDI-201
Cleveland, Ohio 44106
(216) 229-8600

Region VI

Ohio Region VI Sickle Cell Program
Akron Children's Hospital
One Perkins Square
Akron, Ohio 44308
(330) 543-3521

Sickle Cell Disease Selected Resource Information for School Personnel

Cynthia K. Silkworth, et al. (eds.),
*Individualized Healthcare Plans for the
School Nurse: Concepts, Framework,
Issues, and Applications for School
Nursing Practice*, available at:
<http://www.schoolnursebooks.com>.

National Institutes of Health,
The Management of Sickle Cell Disease,
available at:
http://www.nhlbi.nih.gov/health/prof/blood/sickle/sc_mngt.pdf.

The Sickle Cell Information Center,
<http://scinfo.org>.

Sara Day and Elisabeth Chismark,
"The Cognitive and Academic Impact of
Sickle Cell Disease," *Journal of School Nursing*,
Retrieved from
<http://www.iascnapa.org/docs/ArticleSaraDay.pdf>.

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and Thalassemia Program, Nationwide
Children's Hospital, Columbus, Ohio.

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Pediatric Hematology-Oncology,
George and Marie Backus Children's
Hospital at Memorial University Medical
Center, Savannah, Georgia.



Ohio Department of Health
Sickle Cell Services Program
<http://www.odh.ohio.gov>