

What You Should Know About Sickle Cell Disease (SCD)

Boston Public Schools (BPS) is committed to identifying students with Sickle Cell Disease (SCD) and working with them and their families to set up individual supports needed for each child, through the combined efforts of Welcome Services, Special Education and School Health Services, and other departments. BPS works to ensure that all children have the ability to access and receive a high quality education. We aim to raise awareness of what SCD is and what it means for students who have it. We have a goal of reducing the stigma, often racially charged, that surrounds SCD, and often prevents families of students with SCD from reaching out for school supports.

What is Sickle Cell Disease (SCD)?

SCD is a group of inherited blood disorders that affects red blood cells. Normal red blood cells are round and can easily move through the small tubes (blood vessels) that transport blood through the body. In people with SCD, red blood cells form a c-shape that looks like a farm tool called a sickle. These sickle shaped cells are hard and sticky, and can get stuck in small blood vessels and block the flow of blood to parts of the body.



What causes Sickle Cell Disease?

People are born with SCD. They inherit it from their parents in the same way they might inherit their parents' eye color or hair color. You cannot catch SCD by spending time with someone who has it.

What are common health problems for people with Sickle Cell Disease?

- *Pain episode or crisis:* Sickle cells can clog the small vessels and block blood flow, causing sudden, mild to severe pain that can last any length of time.
- *Infection:* People with SCD, especially infants and children, are more likely to experience harmful infections such as flu, meningitis, and hepatitis.
- *Hand-foot syndrome:* Swelling in the hands and feet, often along with a fever.
- *Eye disease:* SCD can affect the blood vessels in the eye and lead to long term damage.
- *Acute chest syndrome:* Blockage of the flow of blood to the lungs can cause acute chest syndrome. Symptoms include chest pain, coughing, difficulty breathing, and fever. It can be life threatening and should be treated in a hospital.
- *Stroke:* Sickle cells can clog blood flow to the brain and cause a stroke. A stroke can result in lifelong disabilities and learning problems.

Who is affected by Sickle Cell Disease?

SCD affects about 100,000 Americans. It is most common in people of African-American and Hispanic-American descent. SCD occurs in about 1 out of every 365 Black or African-American births and in about 1 out of every 16,300 Hispanic-American births.

How does BPS support students with Sickle Cell Disease?

BPS has a policy pertaining to supporting students with SCD and their educational needs. [Click here to read the full policy](https://bit.ly/2GLuAw8) or visit: <https://bit.ly/2GLuAw8>. In short, under the new policy, BPS will evaluate every student with SCD and—while comprehensive evaluations are pending—will provide interim *services and supports* to students with SCD *immediately* once they know the child has SCD so s/he is able to safely attend school. BPS will provide each child any additional *services they need* based on the completed evaluations, and these will be provided through formal 504 Plans and/or Individual Education Programs (IEP's). BPS will then work with families to continually update the health/safety-related services in these plans. BPS will track the progress of children with SCD to make sure that any sudden changes in performance (because of absences or other issues) are detected and addressed quickly.

Additional Questions? Contact:

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Resources: Centers for Disease Control, Sickle Cell Disease Association of America, American Society of Hematology, Greater Boston Sickle Cell Disease Association, St. Jude Children's Research Hospital, Photo from Dana-Farber/Boston Children's Hospital Cancer and Blood Disorders Center, (<http://www.danafarberbostonchildrens.org/conditions/blood-disorders/sickle-cell-disease.aspx>)