

Sickle Cell Disease "Learn more page"
Web page on <http://dshs.texas.gov/newborn/sickle.aspx>

Learn More About ~~This Condition~~ Sickle Cell Disease

General Information

[The Infant and Young Child With Sickle Cell Anemia](#)

[Sickle Cell Anemia: A Parent's Guide for the School Age Child](#)

[Anemia de células falciformes: Una guía para padres de niños en edad escolar](#) (Spanish)

[Sickle Cell Disease: A Resource for the Educator](#)

[Things To Know About Sickle Cell Trait](#)

[Lo Que Debe Saber Sobre El Rasgo Falciforme](#) (Spanish)



Sickle cell disease is a hereditary blood disorder that affects hemoglobin, the substance in red blood cells that carries oxygen.

Types of Sickle Cell Disease

[Hemoglobin Sickle C Disease](#)

[Sickle Beta Zero Thalassemia](#)

[Talasemia Falciforme Beta Cero](#) (Spanish)

[Sickle Beta + Thalassemia](#)

Commented [FD1]: For each type, review the "what to expect" section. I would suggest modifying language.

Potential Complications

Acute [Chest Syndrome](#)

[Síndrome de Pecho](#) (Spanish)

[Aplastic Crisis](#)

[Crisis Aplástica](#) (Spanish)

[PAIN in the Child with Sickle Cell Disease](#)

[DOLOR en el Niño con Enfermedad de Célula Falciforme](#) (Spanish)

[Pneumococcal Infection and Penicillin](#)

[Infección Neumocócica y Penicilina](#) (Spanish)

[Priapism](#)

[Priapismo](#) (Spanish)

[Sickle Cell Anemia and Stroke](#)

[Anemia De Célula Falciforme y Ataques](#) (Spanish)

[Splenic Sequestration Crisis](#)

Commented [FD2]: Would change name to "acute chest syndrome" throughout document

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Types of Sickle Cell Disease

[Hemoglobin SS Disease \(Sickle Cell Anemia\)](#)

[Hemoglobin Sickle C Disease](#)

[Sickle Beta Zero Thalassemia](#)

[Talasemia Falciforme Beta Cero \(Spanish\)](#)

[Sickle Beta+ Thalassemia](#)

Other Resources

Education

[American Society of Hematology \(general and health care providers\)](#)

[Centers for Disease Control and Prevention](#)

[National Heart, Lung, and Blood Institute](#)

[Sickle Cell Disease Management Tool](#)

National Recommendations for Sickle Cell Management

The fourth edition of [The Management of Sickle Cell Disease](#)—developed by physicians, nurses, psychologists, and social workers who specialize in the care of children and adults with sickle cell disease—describes approaches to counseling and also to management of many of the medical complications of sickle cell disease.

In 2014, the National Institutes of Health released an [expert panel report](#) from a team of physicians of various specialties to review updated evidence-based management of sickle cell disease.

Since 2004, Congress has authorized the Health Resources and Services Administration to carry out the Sickle Cell Disease Treatment Demonstration Program in order to improve care and health outcomes for sickle cell disease. Click [here](#) to view their 2017 report and associated resources.

Sickle Cell Specialists in Texas ~~Health Professionals~~

- [Pediatric Hemoglobinopathy Consultants](#) (PDF)
- [Genetic Services Provider List](#)

Other Resources

[American Society of Hematology \(general and health care providers\)](#)

[Centers for Disease Control and Prevention](#)

[National Heart, Lung, and Blood Institute](#)

[Sickle Cell Disease Management Tool](#)

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Commented [FD8]: Hyperlink: <http://www.hematology.org/Clinicians/Priorities/4669.aspx>

Commented [FD9]: Hyperlink: <https://www.cdc.gov/ncbddd/sicklecell/index.html>

Commented [FD10]: Link: <https://www.nhlbi.nih.gov/health/health-topics/topics/sca>

Commented [FD11]: Hyperlink: http://sickleoptions.org/en_US/

Commented [FD12]: Can consider removing this, but it is still available on NIH website and is slightly different than 2014 guidelines. and replace with 2014 guidelines (short version) or put both links. 2014 NIH Sickle Cell Guidelines: https://www.nhlbi.nih.gov/sites/www.nhlbi.nih.gov/files/Evd-Bsd_SickleCellDis_Rep2014.pdf

Commented [FD13]: Hyperlink to 2014 guidelines (short version): https://www.nhlbi.nih.gov/sites/www.nhlbi.nih.gov/files/Evd-Bsd_SickleCellDis_Rep2014.pdf

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Commented [TI15]: Hyperlink to 2017 SCDTDP page: <http://www.nichq.org/project/sickle-cell-disease-treatment-demonstration-program>

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Commented [FD20]: Link: <https://www.nhlbi.nih.gov/health/health-topics/topics/sca>

Commented [FD21]: Hyperlink: http://sickleoptions.org/en_US/

Sickle Cell ~~Direct Service Agencies~~**Associations in Texas**

Austin/Houston/San Antonio

[Sickle Cell Association of Texas](#)

Marc Thomas Foundation

One Highland Center

314 E. Highland Mall Blvd., Suite 411

Austin, TX 78752

2500 East T.C. Jester Blvd., Suite 150A

Houston, Texas 77008

Email: info@sicklecelltx.org

Phone: ~~512-458-9767~~ or 1-877-994-HOPE (toll free)

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<http://www.sicklecelltx.org/>

Fort Worth

Maroon 9

4612 Granbury Road

Fort Worth, TX 76133

Email: info@maroon9sicklecell.org

Phone: 817-797-2526, 817-353-6893

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<http://www.maroon9sicklecell.org/>

~~Other Sickle Cell~~ Other Support Groups

Above the Crisis [\(video\)](#)

The Otis Uduebor Sickle Cell Foundation

P.O. Box 471

Rowlett, TX 75030

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<http://mentalhealthchannel.tv/episode/above-the-crisis>

Commented [FD25]: Link:
<http://theotisfoundation.org/index.html>

[Sickle Cell Association of Houston](#)

4014 Market Street

Houston, TX 77020

Email: ~~care@sicklecellhouston.org~~

SOS Sickle Cell Parent Support Group

P.O. Box 1251

Pearland, TX 77588

Commented [FD26]: Link: <http://sicklecellsupport.org/>

[Sickle Cell Disease Association of Tarrant County](#)

JPS Professional Building

1350 S. Main, Suite 3600

Fort Worth, TX 76104

Email: ~~info@sedatarrant.org~~

[Starlight Children's Foundation](#)

2049 Century Park East, Suite 4320

Los Angeles, CA 90067

Newsletter

~~The Sickle Cell Rapper is created by The Children's Sickle Center, San Antonio, Texas. It is intended to be informational and does not have the endorsement of the Texas Department of State Health Services. The current edition is provided below. For previous editions or questions related to information in the newsletter, contact their office at 210-567-7477.~~

~~[Fall 2015 \(PDF\)](#)~~

~~PDF files must be viewed/printed with [Acrobat Reader](#).~~

Other Hemoglobin Disorders

~~[Homozygous Beta Thalassemia Major also known as Cooley's Anemia](#)~~

~~[Hemoglobin C Disease](#)~~

~~[Hemoglobin E](#)~~

External links to other sites are intended to be informational and do not have the endorsement of the Texas Department of State Health Services. These sites may also not be accessible to persons with disabilities.

Last updated September 6, 2016

Commented [FD27]: Consider removing completely or moving to under support groups section.

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To learn about other disorders of hemoglobin, please [click here](#). And then get to this list.
If we leave on this page, we may want to move all the way to bottom.