

# The Rapper

The Children's Regional Sickle Cell Center, San Antonio  
University of Texas Health Science Center San Antonio

## How Does an Echocardiogram Help in Caring for Patients with Sickle Cell Disease?



Sickle Cell Disease was originally described by a cardiologist, James B. Herrick in the year 1910. Although this is a chronic and lifelong disease resulting from an alteration in hemoglobin, medical management helps patients survive painful intermittent attacks. We know that the disease affects many organ systems in patients who have symptoms related to blood vessel occlusion. As these symptoms or episodes continue to occur, a vasculopathy, or disease of the blood vessels, develops. This vasculopathy affects the lung vasculature and patients can develop pulmonary hypertension (increased pressure in the lung arteries). Organ failure or dysfunction, including cardiac dysfunction, may also develop over time. Although increases in lung artery pressures can be associated with abnormal left sided heart function, recent studies have produced evidence suggesting that abnormal cardiac function and pulmonary hypertension affect the overall long term survival in patients independent of each other.

An echocardiogram, or a heart ultrasound, is a simple and painless procedure which can be used to assess heart function and estimate heart and lung pressures. The anemia associated with sickle cell disease essentially makes the heart "work harder" by creating a need for more output from the heart. The changes associated with this increased load on the heart can be readily evaluated by echo cardiography. Initially the heart becomes dilated and eventually the heart muscle thickens in response to these increased needs. Most patients can tolerate these changes without having any major effect on how their heart functions and without noticing any impact on their daily life. Those patients whose heart function is adversely affected are thought to have an increased mortality risk regardless of clinical symptoms. We know that systemic hypertension, or high blood pressure, can also affect cardiac function thus emphasizing the importance of weight management and prevention of obesity in patients with sickle disease. If an abnormality is detected by echocardiography, it may permit time for earlier medical intervention which could in turn allow for better long term survival. An echocardiogram, in combination with clinical assessment, can serve as a useful guide in managing patients with sickle cell disease not only during an acute crisis but as a way of following a patient's progress. Many of the studies regarding heart function and pulmonary hypertension in sickle cell disease have been performed in adults. On going studies and clinical trials may prove to be useful in determining treatment for both adults and children with sickle cell disease. Continued follow up with your primary physician and hematologist is important.

Elaine Maldonado-Campbell, MD  
Clinical Assistant Professor of Pediatrics  
University of Texas Health Science Center San Antonio  
Division of Cardiology

### Resources:

[American College of Cardiology](#)  
[American Heart Association](#)  
[Clinical Trials.gov](#)



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## *Congratulations 2007 High School Graduates!*

*The Staff of the Children's Regional Sickle Cell Center would like to congratulate you on your scholastic achievements!*

*Tyrell, Tiana, Angel, Rahman, Angelica*





## Accommodations for Children with Sickle Cell Disease in School

(Adapted from Sickle Cell Information Center website: [www.scinfo.org](http://www.scinfo.org))

A child with sickle cell disease (SCD) may qualify for accommodations under the Section 504 program or for special education under the category of Other Health Impairment (OHI). If the child does not qualify for these programs, the school nurse can also write accommodations under an Individual Health Plan (IHP).

These are some possible accommodations that may be considered for a child with SCD. Some of these may not apply to your child, and many other accommodations may be available based on your child's individual needs.



**Accommodation:** Two sets of books, one for home and one for school

*Why?* Students with SCD may have unplanned absences due to their illness. Having an extra set of books at home allows the student time to study and stay caught up with their assignments.

**Accommodation:** Student will be assigned a decreased workload when absent from school for clinic visits, hospitalizations, or complications related to SCD. Focus should be on quality vs. quantity of make-up work.

*Why?* Stress can trigger a pain episode. After an extended absence from school, the student may feel overwhelmed and worried about making up the missed work. Modifying the work load may prevent stress and help the student be more successful in catching up with the rest of the class.

**Accommodation:** The student may be assigned a case manager, social worker, or buddy at school to keep him informed of class activities.

*Why?* Due to frequent absences, the student may miss out on school functions such as field trips or picture day. The case manager or buddy can call the student during absences to keep him informed about special events.

What should you do?

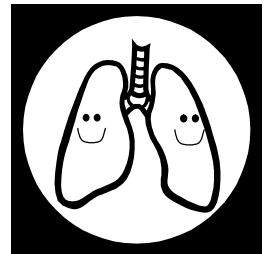
At the beginning of every school year, educate your child's school about sickle cell disease. Advocate for your child to be enrolled in the Section 504 program. This will probably require a letter or form from the doctor, and we will be happy to help you with this! For more information about Section 504 of the Rehabilitation Act, contact the Texas Education Agency ([www.tea.state.tx.us](http://www.tea.state.tx.us)) or your local school district. You may also reference [www.wrightslaw.com](http://www.wrightslaw.com), an online resource for special education laws.

### **Happy Lungs ☺ : The Family Asthma Program**

*Program Goal: A social worker-driven program aimed to decrease the severity and frequency of asthma symptoms in children between the ages of 5 and 11 years old. Families will become informed and empowered to take control of their child's asthma. The child and family will attend group & individual sessions with a bilingual Asthma Counselor/Social Worker. The program runs a span of at least 12 months. At this time, the program is at no cost to families.*

A child must be:

- 5-11 years old
- diagnosed with moderate to severe persistent asthma
- willing to meet quarterly with an Asthma Counselor at CHRISTUS Santa Rosa Center for Children & Families  
(to attend group & individual sessions)



What the family gets:

- one-one in-depth family interview with risk assessment
- 1 Adult and Child group class
- Individual family sessions
- Free dust mite-proof mattress cover and pillow cover if child is dust mite-allergic
- Monthly follow up by telephone or face-to-face
- 12 months total intervention time

For further information contact:

Donna Doulton, RN, BcSN

Nurse Coordinator

The Children's Regional Sickle Cell Center

210-704-3454

### **Asthma Education Class**

Debbie Long, CRT Asthma Educator, teaches asthma education Monday thru Fridays at 10a.m. at Christus Santa Rosa Children's Hospital. For further information and location of class please contact Debbie at 210-704-2465



The Children's Regional  
Sickle Cell Center Team

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Social Work

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## Announcements

### Thank you!

Thank you Kiwanis Club of the Greater Randolph Area, Inc. for your contribution of \$500.00 to the Children's Regional Sickle Cell Center

This contribution and all others received by the center will be utilized for educational materials, education and awareness of sickle cell disease.



2007 Sickle Cell Holiday Party

December 5, 2007

Christus Santa Rosa Children's Hospital

5th Floor Child Life Center

RSVP to Donna Doulton at

210-704-3110

Resources:

American College of Cardiology

American Heart Association

Clinical Trials.gov

