

2011 SICKLE CELL CAMP: CAMP Cell-A-Bration!

We had 8 campers this year. The most EVER! Camp was held at "Camp for All" site in Burton, TX, on August 7th through August 12th 2011. We thank all our volunteers that make it a huge success.



2011 Sickle Cell Christmas Party is almost here!!!



December 7, 2011



Time: 6pm – 9pm
Location: Center for Children's & Family; Goldsbury Bldg; 5th Floor
(bldg across from Kidstop/Gift Shop)

***Ticket will be required!!**



Please contact Albert Estrada, Admin. Assoc. at 210.567.7468 or email: estrada2@uthscsa.edu for more information.



Hematologist: Melissa Frei-Jones, MD 210-704-7477	Nurse Coordinator: Donna Doulton, RN 210-704-3110	Research Coordinator: Alexis Boggess 210-567-7469
Psychology: Leanne Embry, PhD	Social Worker: Sally Wiard, LCSW 210-704-3443	Genetic Counselor: Martha Thomas, MS
	Administrative Associate: Albert Estrada 210-567-7468	

Telephone (210) 704-2187 or 1-800 227-3618 Fax (210) 704-2396
<http://www.pediatrics.uthscsa.edu/hem-onc/index.asp>

THE SICKLE CELL RAPPER

The Children's Regional Sickle Cell Center

FALL 2011

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Spike IT For Sickle Cell

First annual sand volleyball tournament was held on Saturday, September 24, 2011 at the University of Texas Health Science Center, main campus. Several teams participated in the tournament with all proceeds going to support transportation to Camp Cell-A-Bration and other educational program developments. Thank you to Dr. Melissa Frei-Jones and Donna Doulton for organizing this tournament and to everyone who volunteered to make this a fun filled day. Book your calendar for the 4th Saturday in September 2012 for the 2nd annual tournament. Remember September is Sickle Cell Awareness month!!



Hydrea was this years winning Team!!





The San Antonio Bar Association, Texas RioGrande Legal Aid, & Disability Rights Texas present

SPECIAL EDUCATION CLINIC

Including a **Know-Your-Rights** Presentation & **Ask-A-Lawyer** Session

October 27, 2011
5:30 pm

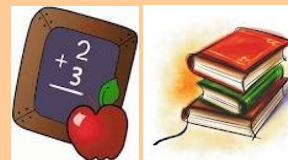
Texas RioGrande Legal Aid
1111 N. Main
San Antonio, TX 78212

- Learn what rights children with disabilities have in schools
- Learn how to advocate your child in the special education system
- Get free *one-on-one* time with an attorney to help you understand the special education process, to answer your questions, and to develop a strategy to address your child's special needs.

Call Laura Pope at Texas RioGrande Legal Aid for eligibility information and registration.
Prompt registration is appreciated!



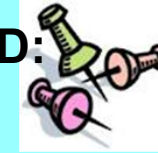
**Register
to
Attend**



**By calling:
210-212-3746**



BULLETIN BOARD:



Donna Douulton, RN will change her work schedule for the New Year 2012.

Tuesday – Friday 7:30am – 3:30pm

REMINDER:

Medications will NOT be filled after hours, weekends, or during holidays!



My name is Albert Estrada, Administrative Associate to the Sickle Cell team! Many of you may know me by voice when I call to confirm your child's appointment. Another method to communicate appointment times or other issues is by email. **For appointment confirmations, calls will still be made.** There have been many times when I am unable to reach you I would like to encourage all to provide me with a email address (if available). Email also serves as a great tool when you need to get a hold of us for ALL **non-emergency** inquires. We are prompt in responding to ALL emails (M-F 8am-5pm). We require a written consent form which can be mailed to you or obtained at clinic visit.

Important Information About Provider-Patient/Caregiver Email Communications will be available to you upon request. You can always call or ask for more information about email communication by calling Albert Estrada Admin. Assoc at 210.567.7468

End Tidal CO2

If admitted to CHRISTUS Santa Rosa Childrens' Hospital:
End Tidal CO2 device is to be used with all IV pain medication. It looks like oxygen tubing but it has a plastic flap that will fall just below the nostrils.



Immunizations:

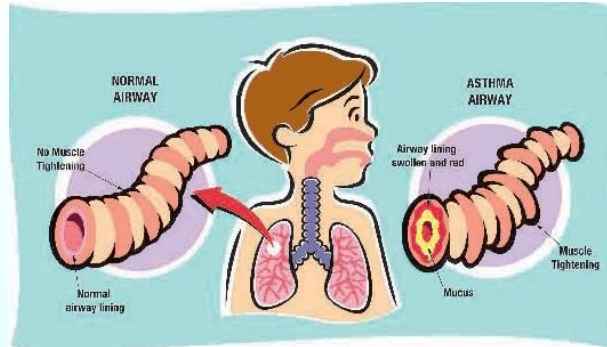
As of February 2011 US Department of Health and Human Services recommends Prevnar-13 (PCV13) to replace Prevnar-7 (PCV7). Prevnar-7 was given to babies at 2 months, 4 months, 6 months and between 12-15 months. Prevnar protects against pneumococcal disease. Prevnar-13 is not the same as Pneumovax-23 which is specifically given to children with sickle cell disease at age 2 years and then boosters every 5 years thereafter. PCV 13 is available at your PCP office but Pneumovax-23 is given in the Sickle Cell Clinic.

Emergency Department:

For patients who are 16 years of age or older. Remember you must call hematologist/oncologist on call at 210-704-2011 **BEFORE** you go to CHRISTUS Santa Rosa Children's Hospital otherwise you may be redirected to the Adult Emergency Department (ED). We are privileged to be able to still use the Children's ED as the cut-off age in Children's ED is 16 years of age.

Speaking of ED – remember to call the Sickle Cell Nurse (210-704-3110) to let her know that you and your child where in ED in case you need further assessment.

BACK TO BASICS #4:



EARLY WARNING SIGNS:

- Runny Nose
- Coughing
- Shortness of Breath
- Not Sleeping Well
- Poor Appetite
- In patients with sickle cell, may have chest pain or back pain

HOW TO TREAT AN ATTACK:

- Follow your ASTHMA ACTION PLAN.
- Use your RESCUE medications

ASTHMA MEDICATIONS	
CONTROLLER Flovent Pulmicort Symbicort Advair Dulera	RESCUE Albuterol Proventil Ventolin Xopenex ProAir
Always rinse mouth and wipe face after using Controller	
Controller Meds are taken everyday regardless of symptoms	Rescue meds are taken during an asthma attack, prior to exercise or for increased asthma symptoms such as cough or wheezing
Controller medications do not treat acute symptoms such as wheezing and cough but can prevent them if taken every day.	

TRLA

Texas RioGrande Legal Aid

YOU AND YOUR CHILD HAVE RIGHTS!
IMPORTANT INFORMATION ABOUT SPECIAL EDUCATION

Your child has the right to a free and appropriate education.

Schools must provide free instruction and support services to help children with disabilities learn.

The school must educate your child in the least restrictive environment.

Your child has the right to be educated as much as possible with non-disabled students, and as close to home as possible.

You have the right to ask the school to evaluate your child for special education.

Give the school a written request for an evaluation if you think your child has a disability. If you think the school's evaluation is inaccurate, then ask the school to pay for an independent educational evaluation by a qualified person who does not work for the school.

You have the right to see your child's records, and to make sure that they are accurate.

If you believe that your child's school records are inaccurate, misleading, or violate your child's rights, ask the school to amend them.

The school must protect your child's health and safety.

The school cannot use any practice that is intended to injure, harm, demean, or deprive your child of basic human necessities.

The school must give you a written notice about your child's education.

The school must send you a written notice of plans for your child's education and about your rights.

You have the right to meet with teachers and other school staff to plan your child's education.

If your child needs special education, the school must meet with you at least once a year to make an Individualized Education Plan (IEP). You may ask for more meetings. You may bring other people to these meetings, such as your child's doctor or advocate.

You have the right to disagree with the school regarding your child's education plan.

If you disagree with the school's plan, you have a right to meet with the school again within 10 school days to try to work things out. If the problem is not resolved, ask for mediation, file a complaint with the Texas Education Agency, or ask for a due process hearing.

More details may apply to you. If you have questions or need legal help, please contact TRLA at 1-888-988-9996.

INFECTION

The child with sickle cell disease will get colds, sore throats and ear infections just like other children. These minor infections are not serious. Some more serious infections are more likely to occur in the child with severe sickle cell disease (Homozygous SS and SBeta Thalassemia Zero) and include septicemia (infection of the blood), meningitis (infection around the brain), pneumonia (acute chest syndrome or infection in the lungs), and osteomyelitis (infection in the bone.).

A child with septicemia may not seem very sick. A fever of 101° F or higher may be the only symptom at first. Other symptoms include unusual sleepiness, rapid breathing, pale color, vomiting, stiff neck and diarrhea. Septicemia is more common in young children, but may occur in older children with sickle cell disease. Early and aggressive treatment is the best hope for recovery from this sometimes fatal complication.

Meningitis is very similar to septicemia in its symptoms and can also be fatal. The child with this problem is usually very irritable or excessively sleepy and may have a stiff neck or seizures.

Pneumonia can be mild with very few symptoms or it can be quite serious. The symptoms are high fever, rapid breathing, and shortness of breath, chest pain, abdominal pain and cough.

Osteomyelitis causes fever, pain, swelling and or redness over a bone. A child will often have a fever of 102° F or more. If this complication occurs and treatment is delayed, serious and permanent damage to the bone or joint can occur.

All the infections named here are treatable and complete recovery is possible. It is also true that even with treatment, permanent disabilities and sometimes death can result. A doctor should see the child with symptoms of a serious infection as soon as possible. Early recognition and treatment of infection offers the best chance for complete recovery. Pneumococcal vaccines (Pneumovax and Prevnar) are given to decrease the risk of blood infections (septicemia), meningitis, and pneumonia.

FEVER

Fever is a normal response of the body to infection. Fever is usually due to a minor illness, but it may be the first sign of a very serious infection. When fever first begins, it is impossible to tell how serious the infection is. The child with a severe form of sickle cell disease (Homozygous SS and SBeta Thalassemia Zero) is more susceptible to serious infections such as septicemia (infection of the blood or blood poisoning). If the child does have septicemia, treatment must be started immediately to save his/her life. Fever may be the first symptoms of septicemia, so it is important for parents to know what to do when their child seems sick and has a fever.

Whenever a child seems sick, their temperature should be checked with a thermometer. Parents should always have one at home or with them if they are away from home.

1. IF THE TEMPERATURE IS 101°F OR HIGHER take the child immediately to a facility that gives emergency care. Be sure to tell the doctor what type of sickle cell disease your child has.
2. WHEN A CHILD HAS A FEVER AND OTHER SYMPTOMS such as pale color, trouble breathing, unusual sleepiness, chest pain, severe cough, abdominal pain, diarrhea, or vomiting, your child should be taken to the doctor immediately for emergency care.
3. SUDDEN WORSENING OF ANY SYMPTOMS IS ENOUGH REASON TO CALL OR SEE THE DOCTOR SOON.
4. IT IS IMPOSSIBLE TO KNOW HOW HIGH THE FEVER IS BY FEELING THE SKIN. The child's temperature must be taken with a thermometer. Do not give medication for fever before checking the temperature with a thermometer.

Fever medication makes a child feel better and reduces the fluid losses from the body, but it does not treat the cause of the fever. If a child has a fever of 101°F or more, you may give the child medication for fever and take the child to a facility that provides emergency care.

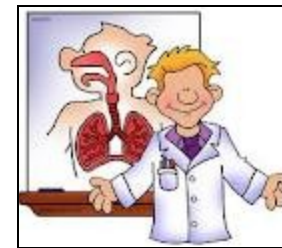
There are other things to do when a child has a fever. Dressing the child in light clothing, keeping the room at 70 degrees, and giving a lukewarm bath may help lower the fever. If the child is sleeping, use only light covers. Anything that causes shivering should be avoided because it will make the fever rise. A child with fever needs to drink lots of fluid. If a child has a temperature of 101°F or higher, it is not safe to wait and see if the fever comes down. The child should be taken to the doctor for immediate treatment.

Texas Department of State Health Services, Newborn Screening.

For more information: www.dshs.state.tx.us.org

ASTHMA:

ASTHMA: A chronic lung disease that cannot be cured, but may improve over time with age. It is controlled by taking CONTROLLER medication and RESCUE medication. People with asthma have sensitive airways. Things in the environment can TRIGGER an asthma attack. If asthma is not controlled, it may lead to frequent ER visits or hospital stays. Poor asthma control may lead to death. For patients who also have sickle cell disease, asthma can trigger episodes of severe pain and acute chest syndrome which require ER visits and hospitalizations.

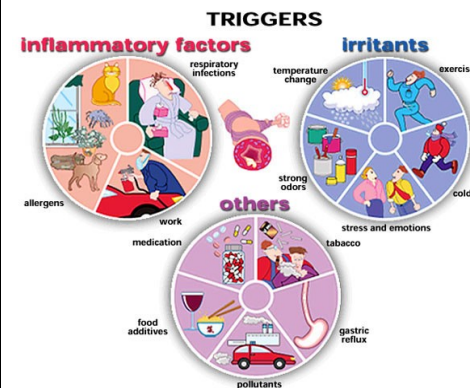


SIGNS AND SYMPTOMS:

- Coughing • Shortness of Breath
- Wheezing • Tight Chest or Chest Pain
- Unable to exercise without symptoms
- Prolonged coughing or wheezing after viral infections

WHAT CAUSES AN ASTHMA ATTACK?

- TRIGGERS such as colds, smoke allergies or exercise can cause an asthma attack.
- Since everyone is different, it is important to know what TRIGGERS our child's asthma



WHAT HAPPENS DURING AN ASTHMA ATTACK?

- The airway lining becomes swollen
- Muscles around the airway tighten, make the airway smaller
- Thick mucus forms, blocking small airways

