Safe Summer Fun

Helpful Tips:

THINK SAFETY FIRST

These tips can help you keep your child safe and add to general safety advice for your child's stage of development. Adapt these tips to meet the needs of your child and family. What works now may change as your child grows and develops. Be a role model. Children will do what you do. If you wear your helmet, they will too.

Tips for Using This Flyer:
1. Give a copy to the people who care for your child. Mark tips that may help them.
2. Talk with your child's care team including your child's health care provider, school nurse, principal, teacher, school staff and other caregivers.
3. Involve your child. Talk about the steps you'll take. Ask your child "what if" questions to help them learn to problem solve.
4. One of the most important safety tips for children with Sickle Cell Disease is to check **all** fevers and respond appropriately. Talk with your child's doctor about fevers and when you should take your child to the emergency room if she has a fever.
5. In all activities, balance your child's active, rest and sleep times. Adjust them as needed.

Fall Safety:
1. Be aware if your child is tired from an imbalance between her oxygen supply and demand, this can increase your child's risk for falls.
2. Help your child choose and take part in activities that fit her endurance level. Talk with your child's health care provider for recommendations.
3. Avoid having your child take part in contact sports to reduce the risk of causing pain episodes.

Water Safety:
1. Avoid cold water temperatures (below 84◦). Cold temperatures are known to start pain crises.
2. Observe your child's facial and skin color for any signs of chilling.
3. Always have an adult watch your child closely around water (even if a lifeguard is present).
4. Have your child wear a life vest each time he is on a boat, on a dock and near open water like rivers or lakes.

Car Safety:
1. Babies should ride in a **rear facing** car seat until at least one year of age **and** at least 20 pounds.
2. Toddlers and preschoolers, over one year **and** 20-40 pounds, use a convertible car seat in the forward-facing position.
3. Children, 40 to 80 pounds, should use a belt-positioning booster seat.
4. Children over 8 years, at least 4'9" tall, and 80 pounds, use a lap and shoulder belt.

Bike Safety:
Make sure your child always wears a helmet and other safety gear including kneepads, elbow pads and wrist guards for roller blading and skateboarding, and knee and elbow pads for scooter riding**.**

Preventing Vaso-occlusive Pain Crisis:
1. Fly only in pressurized planes.
2. Have your child rest when he is fatigued.
3. Make sure your child gets all the advised immunizations. This includes a yearly flu shot.
4. Try to reduce stress for your child.
5. Give your child all the medicines he has been prescribed.

Have your child drink lots of fluids to avoid dehydration when he or she:
1. Has a fever.
2. Has pain.
3. Is outside in hot weather.
4. Is very active.
5. Is traveling.

Medical terminology Answers

po = by mouth
qday = once a day
bid = twice a day
tid = three times a day
qid = four times a day
qother day = every other day
sc = subcutaneous (under the skin)
im = intra-muscular (in the muscle)
cbc = complete blood count
sl = sublingual (under the tongue)
od = right eye
os = left eye

THE SICKLE CELL RAPPER

The Children's Regional Sickle Cell Center

Spring/Summer

THE SICKLE CELL RAPPER

CAMP INFORMATION

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Camp for All in Burton, Texas!!!!!!
www.campforall.org

Sunday, August 05 – Friday, August 10, 2012

Completed Applications must be returned:
Sickle Cell Association of Austin
314 E. Highland Mall Blvd, Suite 108; Austin Texas 78752

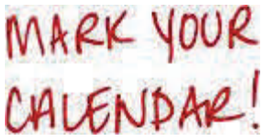
Linda Thomas Wade, President and Co-Founder
Office (512) 458-9767
Fax (512) 458-9714
www.sicklecellaustin.org

Deadline: June 30, 2012

Please include a $35.00 non-refundable application fee due upon receipt of the application. Please submit payment by either Money Order or Cashier's Check payable to the "Sickle Cell Association of Austin"

Sufficient medications for all 6 days is required in original prescription bottle. Parents are responsible for supplying any and all machines and supplies necessary for administering medication and must attend mandatory parent and Camper Orientation Meeting. ***Date to be announced. ***

Please note that there are some changes. All campers should have had a physical within the last six months. PLEASE ASK YOUR PHYSICIAN TO COMPLETE ALL OF THE MEDICAL FORMS.



Announcements:

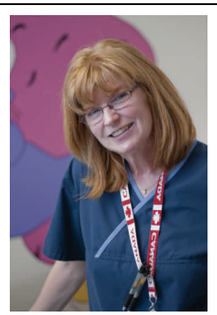
Our 2nd Annual Spike-It for Sickle Cell will be held on Saturday, Sept. 15, 2012
Time: 8am — 4pm
Location: UTHSCSA Volleyball Fields; 7431 Merton Minter Street
(located behind the Spectrum Fitness Center on Floyd Curl Drive)

For more information about this year's event you may contact Albert Estrada, Admin Assist at 210-567.7468 or email him at estradaa2@uthscsa.edu

Our WINNERS last year!

Emily Moses, MD

In July, we will be welcoming Dr. Emily Moses, 3rd year hematology-oncology fellow, to the SCD clinic. Dr. Moses will be helping us care for patients in SCD clinic as she seeks to increase her experience with SCD.



Donna Doulton, RN, BcSN

Starting on July 9th (Monday), Donna will be switching back her hours as follows:

Monday through Thursday 8:00am — 4:00pm (Summer Hours / OFF Fridays)
Hours will go back to school hours in August.

Wednesday remains our primary SCD clinic day with Comprehensive Annuals scheduled for the 2nd Wednesday morning each month. Hospital follow-up and hydroxyurea visits will also be available on Monday's starting in July.

In addition we encourage everyone to please update our office with any changes to your address or phone numbers. And as a courtesy we ask that you please return calls to confirm all appointments so that we can accommodate those who need to be seen.

Thank you, SC Staff

We cannot refill pain medications after hours, holidays or weekends. Please make sure you have a week's supply on hand.

Important Clinic Telephone Numbers

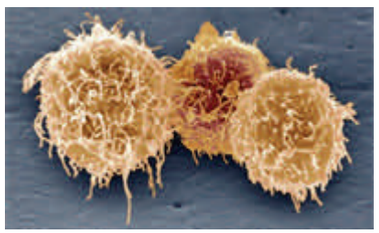
Physician	**Melissa Frei-Jones, MD** Office 210-567-7477
Nurse	**Donna Doulton, RN, BcSN** Office 210-704-3110 Pager 210-235-0578 Fax 210-704-2396 Email: doulton@uthscsa.edu
Social Worker	**Sally Wiard, LCSW** Office 210-704-3443 Pager 210-235-2220
Psychologist	**Leanne Segovia, Ph.D.** Office 210-704-2987
Child Life	**Patti Penet** Office 210-704-2642
Genetic Counselor	**Martha Thomas** Office 210-567-7481 Pager 210-235-0668
Admin Assistant I	**Albert Estrada** Office 210-567-7468 Fax: 210-567-7466 Email: estradaa2@uthscsa.edu
Address	CHRISTUS Santa Rosa Children's Hospital Pediatric Hematology/Oncology 333 North Santa Rosa Street; 8th Floor San Antonio, TX 78207

Back to Basics

Understanding Your Complete Blood Count

A complete blood count (CBC) – sometimes referred to as your "number" –helps you and your doctor monitor some effects of your chemotherapy by measuring cells in your blood in relation to normal ranges. "Normal" ranges provide a reference, but your doctor and nurse will evaluate your specific counts and work with you to determine if there are any problems to address.

A complete blood count measures amounts of 3 types of cells in your blood

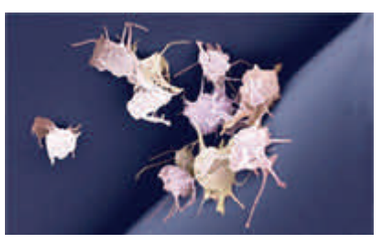


White blood cells

White blood cells protect your body against foreign invaders such as bacteriaBacteria—The smallest forms of life. Bacteria are the most common causes of infections in people with cancer. Some examples of bacterial infection include food poisoning, pneumonia and strep throat.. There are several types of white blood cells in the body. NeutrophilsNeutrophil—The most common type of white blood cell. Neutrophils help the body fight infection. A low white blood cell count usually indicates that the neutrophil count is low. It is easier to get an infection and harder to recover from an infection when the number of neutrophils in the bloodstream is low., a specific type of white blood cell, help protect against and fight certain types of infectionInfection—An invasion of microorganisms such as bacteria or viruses that have the ability to multiply and cause disease..[2] The number of neutrophils circulating in your body is referred to as your absolute neutrophil count (ANC)Absolute neutrophil count (ANC)—ANC refers to the number of neutrophils present in the blood. Neutrophils are particularly important because they defend our bodies against certain types of infection., which provides a measure of your body's ability to fight infection. If your ANC falls below normal, you may have a condition called neutropenia.[1]

Red blood cells

Your body needs oxygen to release energy and keep your organs and tissues healthy. Red blood cells carry oxygen throughout your body using a substance called hemoglobin (hee-mo-glow-bin), also known as Hb. When carrying oxygen, hemoglobin**Hemoglobin (Hb)**—The part of the red blood cell that carries oxygen. A person with a low hemoglobin level may have anemia. Hemoglobin is sometimes written as Hb or Hgb on CBC reports. is the protein that makes your blood red. It also contains iron, which holds the oxygen that is delivered to organs and tissues throughout your body by the red blood cells.[3] A blood test called a hematocrit**Hematocrit (Hct)**—A blood test that measures the number of red blood cells in the bloodstream. The lower the hematocrit, the lower the number of red blood cells in the blood. A person with a low hematocrit may have anemia. Hematocrit is sometimes written as Hct on CBC reports. (hee-mat-oh-crit), or Hct, measures the number of red blood cells in the bloodstream.[4] If your Hb or Hct level is too low, you may have anemia**Anemia**—Anemia is a lower-than-normal number of red cells in the blood. Red blood cells are important because they carry oxygen from the lungs to all other cells in the body. Shortness of breath, fatigue, and weakness are signs of anemia. (ah-nee-mee-ah), which can make you feel tired.[2]



Platelets

Platelets**Platelets**—A type of cell made in the bone marrow. The main function of platelets is to aid in clotting the blood following an injury. help your body stop bleeding by forming clots. People with a low platelet count, a condition called thrombocytopenia**Thrombocytopenia**—A condition resulting from an abnormally low number of platelets (thrombocytes) circulating in the blood. Bleeding and/or bruising may occur if the platelet count is especially low.
(throm-bo-sy-toh-pee-nee-ah), may experience excessive bleeding or bruising.[2]

Cross word puzzle

R	U	T	S	T	A	T	J	O	N	H	R	O	J	U
L	E	L	R	N	I	A	I	I	N	E	S	R	C	R
S	Y	D	E	O	U	R	B	A	I	U	E	I	I	H
F	I	M	N	N	P	O	E	R	R	D	O	G	T	S
B	I	C	D	O	L	I	R	H	O	T	T	I	E	A
A	P	I	K	G	I	A	C	O	N	Y	I	N	N	E
J	C	L	O	L	C	T	L	A	B	I	U	D	E	R
E	X	M	S	Y	E	B	A	A	L	T	Q	I	G	A
F	E	S	R	E	C	L	U	R	H	S	S	S	S	G
H	W	C	E	L	L	S	E	Z	D	W	O	O	E	I
E	X	H	A	U	S	T	I	O	N	Y	M	R	T	F
C	S	H	O	Q	P	C	Z	A	V	S	H	D	V	R
S	I	S	E	R	E	H	P	O	R	T	C	E	L	E
H	H	H	V	R	A	I	R	A	L	A	M	R	D	Z
H	Y	P	O	X	I	A	Y	C	H	Y	Y	R	D	D

ANEMIA	AREAS	BLOOD
CARRIER	CELLS	DEHYDRATION
DISORDER	ELECTROPHERESIS	EXHAUSTION
GENETIC	HEMOGLOBIN	HYPOXIA
INHERIT	JAUNDICE	MALARIA
MOSQUITOES	ORIGIN	RED
SICKLE	TRAIT	TROPICAL
ULCERS		

Match your words

Medical terminology:
What does that mean??!!

Do you know what medical terms go where?

po	left eye
qday	intra-muscular (in the muscle)
bid	complete blood count
prn	right eye
tid	three times a day
qid	twice a day
qother day	every other day
sc	once a day
im	subcutaneous (under the skin)
cbc	four times a day
sl	sublingual (under the tongue)
od	as needed
os	by mouth

Answers on page8

New Data Support Continuing Hydroxyurea for Pediatric Sickle

SAN DIEGO – Mounting data from a federally funded follow-up to the BABY HUG study continue to demonstrate that hydroxyurea is a safe and effective treatment for young children with sickle cell anemia.

The results confirm findings published earlier this year from the Pediatric Hydroxyurea Phase III Clinical Trial (BABY HUG), a randomized, placebo-controlled study sponsored by the National Institutes of Health and by the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

BABY HUG showed that hydroxyurea administered to 9- to 18-month-old children with sickle cell anemia provides significant clinical benefits, including a decrease in pain crises, acute chest syndrome events, and need for transfusion and hospital admission (Lancet 2011; 377:1663-72).

Hydroxyurea is approved to prevent sickle cell complications in adults with sickle cell anemia, but it is not currently indicated for use in children. Dr. Zora R. Rogers discussed the new data during a press briefing prior to a presentation at the annual meeting of the American Society of Hematology.

"We need to complete the data analysis and to critically examine the growth and development of this population with respect to hydroxyurea use," lead author Dr. Rogers said of the follow-up study, which terminates on Dec. 31, 2011. "But on a macroscopic level there [do] not appear to be any differences observed."

In 2008 Dr. Rogers, professor of pediatrics at the University of Texas Southwestern Medical Center, Dallas, and her associates at 14 centers launched the BABY HUG Follow-Up Study I to assess the safety and efficacy of continued treatment with hydroxyurea in infants with sickle cell anemia. The population consisted of 163 children aged 28-44 months who had participated in the original BABY HUG trial and who had completed at least 18 months of randomized treatment of either hydroxyurea or placebo. The researchers collected clinical and laboratory data every 6 months from patient medical records, including use and dosage of hydroxyurea, blood counts, clinical imaging, and frequency of sickle cell-related complications.

Of the 163 families that enrolled children in the follow-up study, 133 (82%) chose open-label hydroxyurea at the beginning of follow-up and every 6 months 65%-75% of the families reported that their children continued to take the drug. No patient developed intolerance or stopped permanently because of toxicity.

Dr. Rogers, clinical director of the bone marrow failure and general hematology program at Children's Medical Center, Dallas, presented preliminary analyses as of Oct. 18, 2011, that amounted to 497 patient-years of follow-up. Compared with children who are not taking hydroxyurea, those who continue to take hydroxyurea have statistically lower rates of pain crises requiring emergency department visits (a rate of 29 vs. 54 per 100 patient-years, respectively), episodic transfusions (18 vs. 34 per 100 patient-years), and hospital admissions for any reason (73 vs. 132 per 100 patient-years), including acute chest syndrome or febrile illness.

In their abstract, the researchers pointed out that the decrease in acute chest syndrome episodes "is similar to the effect demonstrated with hydroxyurea use in the randomized BABY HUG trial in younger infants and consistent with published trials detailing the benefit of hydroxyurea therapy in older children and adults. The decrease in the rate of admission for febrile events in hydroxyurea-treated patients is also comparable to that in the randomized trial, but the reason for this benefit is uncertain."

There were no differences between the two groups in hospitalization rates for painful events, including dactylitis. Two patients in the non-hydroxyurea group each had a stroke. There were also no differences between the two groups in the frequency of a palpable spleen or rate of acute splenic sequestration crises. Through 36 months of follow up, children taking hydroxyurea had persistently higher hemoglobin and mean corpuscular volume and lower white blood cell count and absolute neutrophil count, compared with those not taking the drug.

Dr. Susan B. Shurin, acting director of the National Heart, Lung, and Blood Institute (NHLBI), characterized the findings as important in efforts to get an early handle on the burden of disease associated with sickle cell anemia.

"The internists who inherit the patients who have gone through pediatric practitioners have a powerful sense that they reach adolescence doing pretty well, and then things kind of fall apart," Dr. Shurin said. "The clear evidence that prevention of organ damage and prevention of complications of sickle cell anemia would be much preferable to trying to manage once they develop has been the motivation" for this work.

The BABY HUG investigators "believe that ongoing follow-up of this cohort is essential to continue to define the potential benefits as the children grow and to observe for late toxicity," Dr. Rogers said. "We are in final discussions with the NHLBI for an additional contract in support of 5 more years of follow-up."

The researchers intend to use the current findings "in support of an FDA application potentially to allow an indication for the use of hydroxyurea in very young children," Dr. Rogers said. "We are also hoping that there will be an interest for the use of this medication in a liquid format, because it's very hard to get a 1-year-old to take a capsule."

The follow-up study is funded by the National Heart, Lung, and Blood Institute and by the Eunice Kennedy Shriver National Institute of Child Health and Human Development.

The Oncology Report