



THE SICKLE STAR

Supported in part by Project # 2 H46 MC00240-04-00 from the Maternal and Child Health Bureau, Health Resources and Services Administration

INSIDE THIS ISSUE:

Camping News
A Parent Speaks
Health Fairs & Sickle Cell Outreach

Meet Yana, New LMSW

Summer Volunteer
MTA Promotes Sickle Cell Awareness

Sickle Cell Awareness Month Activities
Cold Weather & Pain

- 1
- 2
- 3
- 3
- 4



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Camping Gaining Ground with Kids

January 2006 came along and we began signing kids up for camp at Paul Newman's Double "H" Hole in the Woods Ranch. Here we are at the brink of boarding the luxury coach bus, off to have the summer of all summers. Approximately thirty kids signed up. Our kids are excited and parents are anxious. Many would think that the kids would cry to leave home, however, it's usually the opposite. Many children have such a great time they don't want to come back home. Perhaps when we advertise we should warn parents about this "phenomenon". Many of our annual returning campers have now aged out of this camp and so they are not able to attend the Double "H" Camp. So for next year we want to urge parents of children who are eligible, ages 6-16 (and will not have a seventeen birthday before they go off to camp) to sign up early.



One of the many fun activities - Camper rides on horseback

A NEWBORN SCREENING STORY

My baby was tested for many disease when he was born. I found out that New York State Department of Health test every baby born in the state of New York. As a parent who recently found out that my child has sickle cell trait, I wanted to know more about this condition called sickle cell disease. So when I received a call and a letter in the mail, I took advantage of the opportunity to schedule and an appointment for genetic counseling. Prior to me getting tested in the first trimester of my pregnancy, I had no idea that my family carries the gene for sickle cell disease. Well, I attended the counseling session and found out that if baby's dad has the trait then we could have a child with sickle cell disease. At that point I wondered about all the other countries in the world that don't have newborn screening, how do they find out something as important as this. I don't have answer, but I am thankful for newborn screening in the State of New York.

Working to Increase Sickle Cell Awareness in Summer

Are health fairs the way to go in order to increase awareness of sickle cell disease and other important health conditions that affect our community? If that is the case then program staff have worked to ensure that the word gets out. Summer 2006 will see a spate of health fairs and our participation and involvement in many of them izations; from foster residency programs to faith-based institutions. Staff also have provided technical assistance to a small faith-based institution that will hold its first ever health fair on July 29, 2006.

PLEASE SUPPORT
 SICKLE CELL AWARENESS
 ASK FOR THIS STAMP
 AT YOUR LOCAL
 U.S. POST OFFICE



We continue to collaborate with the Brooklyn/ Staten Island Blood Services to promote community blood donations so please DONATE..

Give Blood to Fight Sickle Cell Disease
 1.800.933.2566



NEW SOCIAL WORKER/CARE COORDINATOR ON BOARD

Ms. Yana Pennant, is the new Social Worker/Care Coordinator for the Division of Pediatric Hematology/Oncology and Comprehensive Sickle Cell Program. Ms. Pennant is diligently working to make sure critically-ill children, receive all the services they require. She has proven that she is committed to the Division and its programs, but most of all to our families. She conducts psycho-social assessments on the families and plans to develop the support group into a stronger networking community that provides support **for** members **by** members.

Yana will also head up the Division's SCYO (teen support group). The aim is to formalize the group so that it will serve as a transition program. The first official meeting is scheduled for September 8th 2006, at 4:00pm. Yana hopes that the program will "smooth" the transition into adult care, with the greatest ease. She says, "I would like to see individuals with sickle cell claim ownership of the disease, so that together we can advocate for service/changes that will empower people with the disease to live life to its fullest potential."



Ms. Pennant, who served as an intern at Henry Street Settlement House, and more recently worked at North Shore Long Island Jewish Medical Center, is well qualified for the job. She holds a Masters Degree in Social Work from Hunter College School of Social Work. Welcome aboard Yana!!!

ANOTHER YEAR, ANOTHER HIT

Held on Saturday, May 13, 2006, our Vocational/Career Day was a hit. There were twenty patients and family members who attended this event. This annual activity was held from 9:30a.m. to 3:00p.m. on the second floor of the Samuel & Bertha Schulman Institute, 555 Rockaway Parkway. We had many speakers with diverse careers who came with literature and give-a-ways for all in attendance. There were occupations and representatives from Banking & Finance, NYC Dept of Corrections, Fashion Stylist, NYPD, the MTA, NYS Department of Parole, Higher Education, Health & Fitness, to name a few.

Representatives spoke with the youth about their careers for approximately 10-15 minutes, providing inspiring and important information about their respective fields. One particular inspiring talk came from Prof. Earleen Smily of Medgar Evers College. She encouraged the youth to work hard and not be limited by their diagnosis. Her mantra was (work + effort = success). We especially wish to thank all speakers for their time, attention and words of wisdom and most of all for the wonderful give-a-ways they brought for the youth.

WELCOME SUMMER VOLUNTEER

This Summer, Ashley Cadett is volunteering with the Division of Pediatric Hematology/Oncology. She is learning all about the workings of the Division and gaining some valuable information about working with children with chronic illness. Ashley is on her way to 12th grade at William Maxwell High School for Vocational Training. She plans to become a Medical Assistant.

Good luck to you in the Fall.

UPCOMING EVENTS-SAVE THESE DATES!

SEPTEMBER IS SICKLE CELL AWARENESS MONTH

- Every Friday Activities in Brookdale's Lobby
- Project Partner, Interfaith Medical Center - Annual Health Fair - 528 Prospect Place - Saturday, September 9th, 2006
- Sickle Cell Disease & Transfusion Symposium - Brookdale's Alumni Hall - Friday, September 15, 2006: Providers 8am – 10am
Consumers Forum 10am – 12noon
- SCTPN Sickle Cell Walk-A-Thon in Central Park - Saturday, September 16th.
- Brookdale Blood Drive - Brooklyn/Staten Island Blood Center - Alumni Hall - September 22nd, 2006.
- Sickle Cell Awareness Bake Sale – Sept. 25th, 2006 11-2pm
- National Sickle Cell Convention - September 27-30th, 2006, Dallas, TX.

PLEASE MARK YOUR CALENDAR WITH THESE SEPTEMBER DATES

MTA HEIGHTENS SICKLE CELL AWARENESS AND NEED FOR PRECISE BLOOD DONATIONS

The MTA is part of an on-going effort to help save lives in the NYC metropolitan area. As part of its 2006 effort, the MTA is promoting its Transit Blood Donor Program, in conjunction with a campaign to promote Sickle Cell Disease and blood donor awareness in the workplace.

The Community-Based Sickle Cell Project will be working with the MTA to heighten the awareness of Sickle Cell Disease and precise match blood donations in Transit during September, which is Sickle Cell Disease Awareness month. Program staff will be participating in a video which will be used to promote the need for blood as it relates to individuals with sickle cell disease. Project Coordinator, Verna DuBerry Ademu-John, is working with Donna James, Director of Medical Surveillance & Correspondence for the MTA. Ms. DuBerry Ademu-John was asked to be the “subject matter expert” and will be on hand to present the facts about sickle cell disease and respond to some of the myths.

In addition, the MTA is working with the New York Blood Center to highlight the need for precise matched donors.

Have you donated in the last 56 days? Do Your Part. Become a Donor Today!

PROGRAM ANNOUNCEMENTS/HAPPENINGS

Parents Support Group

Every first Thursday of the month, the Division of Pediatric Hematology/Oncology holds its Parent Support Group Meeting. Refreshment is served. We need parents to come out. Next meeting will be Sept. 7, 2006.

Sickle Cell Youth Organization

Come out to our revitalized group meetings, now held on the first Friday each month at 4:00p. m. in Room 346 CHC. Next meeting to be held on September 8th, 2006. Come for refreshment and lots of goodies. For more information please call 718.240.5904.

Free Trait Testing for Uninsured Parents

We continue our partnership with Department of Health—Newborn Screening Program to test parents who are uninsured and whose babies are identified with sickle/hemoglobin trait through Newborn Screening.

Participants request to be tested. Over 80 parents have already been tested.

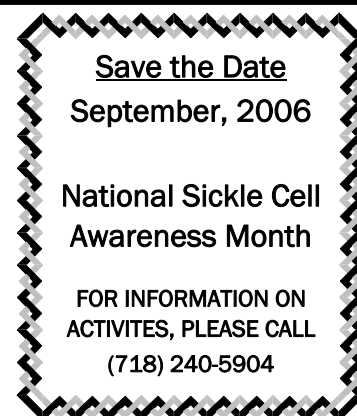
Through this program, we have identified risk factors for eight families and we continue to increase awareness of Sickle Cell Disease and trait in the community.

Someone with sickle cell needs this pint of blood, won't you donate?



ONCE AGAIN WE UNDERSCORE THE IMPORTANCE OF TCD IN STROKE PREVENTION: (TRANS-CRANIAL DOPPLER)

What is this test and why is it important? A TCD screening is recommended at least once per year for children between 3-10 years of age. It is an important test that can determine the risk of stroke in a child living with sickle cell disease. This ultrasound-like test is used to detect areas of increased blood flow in the blood vessels of the brain. When blood vessels in the brain narrow due to damage from sickle cell disease, a stroke can occur. This stroke occurs because there is a problem with the blood circulating to the brain. If the test shows an abnormal result then there is a discussion with your hematologist to assess the need for regular transfusion therapy to decrease the likelihood of the child with sickle cell disease having a stroke. Parents, please call to schedule appointment (718) 240-5904.



Ask the Experts.....

Cold Temperature and Pain Events

Question: Why does cold temperature cause a pain crisis to occur?

Answer: This is a very common problem in sickle cell patients. Most patients find that cold causes the onset of pain. The cold does not directly increase sickling of the red cells but it has two effects on the body that explain the association. Cold increases the use of oxygen by the muscles and this reduces the amount in the red cells. Shivering is an example of the extreme of this effect. Cold also causes the blood vessels to contract down and become smaller to preserve body heat. This directly reduces blood flow and any sickling of red cells causes further slowing of flow. The slower blood flow also reduces further oxygen in the blood and low oxygen causes increased sickling. Dress warm with hat and gloves. Swim only in warm heated pools. You also need to drink lots of water in real cold weather and when swimming because both can also cause dehydration that will increase sickling.

Cold temperature causes reflexes to constrict the blood vessels and slow down the blood flow to hands, feet, & other parts of the extremities, in order to conserve heat for the core functions of the body (brain & trunk). Any condition that slows down blood flow has the potential to trigger sickle cell pain. People can adapt to cold weather and also can dress warmly to reduce heat loss so that blood vessels do not have

these reflex constrictions. A few days every winter, however, have severe snow & ice storms or just severe cold when it is hard to really stay warm no matter what you do.

Warm temperature causes reflexes to open (dilate) blood vessels and send more blood to the skin and extremities to shed heat. This re-distributes blood flow and may shunt blood flow away from parts of the body that need oxygen or need to clear the chemical waste of metabolism. Those parts of the body might then develop sickle cell pain. Sweating helps the body lose heat, but also may lead to dehydration, and dehydration is a common trigger for sickle cell pain. People can adapt to hot weather by keeping to the shade or air conditioning, by drinking a lot of fluids to avoid dehydration, and avoiding excessive exertion while taking frequent rest breaks. (Taken from aplatt@emory.edu)

SINCERE THANKS FROM OUR FAMILIES TO YOU ALL

ALPHA KAPPA ALPHA
ZITWER FOUNDATION
CARLITOS WISH FOUNDATION
COACH TITLEY & CANARSIE HIGH FOOTBALL TEAM
GARGISO FOUNDATION
KINGS COUNTY SICKLE CELL, INC.
STARLIGHT FOUNDATION
TASHA'S LIFE FOUNDATION
TOY KNIGHTS OF AMERICA
MCDONALD'S CHURCH AVE. AND KING'S HIGHWAY
SICKLE CELL THALASSEMIA PATIENTS NETWORK
SICKLE CELL TRUST INC.
BROOKDALE HOSPITAL ADMINISTRATION
THE DEPARTMENT OF FOOD & NUTRITION SERVICES
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MAKE-A-WISH FOUNDATION
PEDIATRIC FLOOR
BROOKLYN KINGS COUNTY LIONS, INC.
DOUBLE "H" HOLE IN THE WOODS RANCH
JACK AND JILL OF BROOKLYN