Sickle Care: The Comprehensive Sickle Cell Program at Brookdale

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Summer 2005

THE SICKLE STAR

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Did You Hear the Good News ~ Community Based Effort Funded

We are proud to announce that the Community-Based Sickle Cell Project has been awarded a grant from the Department of Health & Human Services, Health Resources and Services Administration, Genetic Services Branch. This grant that was initially awarded in 2002, and again in 2003 (for 2 years), was scheduled to end in September 2005. We are one of 17 funded centers in the country and one of a few centers that were awarded the grant for the 3rd cycle in a row and for a new duration of 3 years.

Our collaboration with SUNY Downstate, Kings County Hospital, Interfaith Medical Center and community-based partners; Caribbean Women's Health Association and Brooklyn Perinatal Network, has resulted in tremendous outreach and education, in addition to providing support care and education to patients and families.

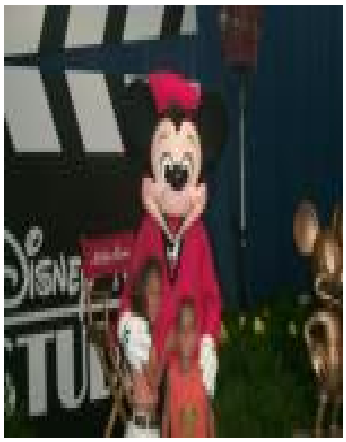
We welcome our new community partner Brownsville Multi-Service Family Health Center and look forward to continuing to increase awareness of sickle cell disease and trait in the community. We also look forward to collaborating with new organizations and building on the relationships we have generated in order to promote education throughout the community. We are also fortunate to have been the only Sickle Cell Center in New York to be re-awarded the New York State Expanded Sickle Cell Services Grant, which is funded until 2010.

CHILDREN'S WISHES COME TRUE AT BROOKDALE

Several of our children with chronic illness have had their dreams come true, thanks to organizations such as "Make a Wish Foundation". This organization grants the wishes of children with life threatening medical conditions. This year our children were granted wishes; from meeting with celebrities such as Halle Berry, to traveling to Hawaii, enjoying shopping sprees, and trips to Disney World; we've had had it all. If your child has not had their wish granted, please contact our office for further information. (718) 240-5904.

Patient Gets Wish Granted With HALLE BERRY

Time At Disney World A Wish Comes True



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

Our Very own "Nurse Hinds" receives award

Lynette Hinds, R.N. , Nurse Coordinator for the Division of Pediatric Hematology/Oncology and Comprehensive Sickle Cell Program was honored by The Carlito's Wish Foundation, a non-profit organization formed to grant wishes to critically-ill children, at their Annual Ball honoring Spectacular Ladies of 2005. Nurse Hinds, as she is affectionately called, has been committed to the Division and its families, but most of all to family-centered care. She promotes peer participation in all health care decision making and advocates the family's interest in the restoration of the patient's health and well being. Ms. Hinds has been at Brookdale for almost 10 years, and is currently working on extending her expertise by becoming a part of the Faculty at Beth Israel College of Nursing. Family members, Brookdale Parents and Staff were on hand to support the Honoree. **Congratulations, Nurse Hinds! Way to Go!!!**

Report on Vocational/Career Day 2005

Held on Saturday, May 21, 2005, our Vocational/Career Day was a hit. There were twenty eight 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. Speakers in a variety of careers came with literature and give-a-ways for all in attendance. There were representatives from architecture, medicine, social services, media, the Brooklyn Public Library, and law enforcement, 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. We especially wish to thank our talented speakers for their time, attention and words of wisdom. We also wish to thank Verity Records, Air Gospel Records, EMI Gospel and Pure Springs Gospel, for their generous donations of T-shirts, CD's, and posters; and Vera Williams of Totally Delicious, (located at 9404 Avenue L) for sponsoring a portion of the truly delicious lunch.

WELCOME SUMMER VOLUNTEERS

This Summer, Marsha Sommervil and Marinah Soudatt are Volunteers working with the Division of Pediatric Hematology/Oncology. They are the best Volunteers ever! Marsha Sommervil is on her way to freshman year at SUNY at Stony Brook, in Long Island. She plans to become a Dermatologist or an Ophthalmologist and Marinah, who plans to be a Veterinarian is going to 11th grade at Clara Barton High School for Health Professions.

Good luck to both of you in the Fall.

UPCOMING EVENTS

Save these Dates!!!

SEPTEMBER IS SICKLE CELL AWARENESS MONTH

- Every Monday & Friday Activities in Brookdale's Lobby
- National Sickle Cell Convention September 7-10th, 2005, Baltimore, MD.
- Health Fair at Project Partner, Interfaith Medical Center - September 10th
- Cake & Pin Sale - Brookdale Lobby - Friday, September 16th
- Sickle Cell Walk-A-Thon in Central Park - Saturday, September 17th.
- Sickle Cell Disease & Transfusion Symposium - Brookdale's Alumni Hall - Fri. Sept. 23rd.
- Brookdale Blood Drive - Brooklyn/Staten Island Blood Center - Alumni Hall - September 30th, 2005.

PLEASE MARK YOUR CALENDAR WITH THESE SEPTEMBER DATES

NEW YORK BLOOD CENTER LAUNCHES COMMUNITY AND FAITH BASED PARTNERSHIP

The New York Blood Center recently launched a Sickle Cell Disease Community Outreach Project to enhance blood donations among African Americans, to better meet the needs of patients with Sickle Cell Disease . It is a fact that there is a disparity between compatible antigen-matched blood that patients with sickle cell need and the supply of blood collected from donors.

Currently, African Americans comprise 8%-9% of blood donors in New York City, while over 27% of residents are African American. The New York Blood Center collaborates with community-based organizations, hospitals, community and political leaders, but is especially looking to faith-based organizations to get their message out to communities of color.

The Sickle Cell Disease Community Outreach Project was recently endorsed by Rev. Dr. Calvin O. Butts III, Pastor of the historical Abyssinian Baptist Church, in Harlem, New York. He is quoted on their informational flier, a quote which states, "The African American community can provide critical help to people with Sickle Cell Disease by being regular blood 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. 1, 2005.

Sickle Cell Youth Organization

SC-YO group meetings are held on the 1st and 3rd Friday of every month @ 4:00p.m. in Room 346 CHC. Refreshment is served. 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. We have a targeted goal of 100 parents and have already tested over 70 parents.

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.

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One pint of blood

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.

Save the Date

September, 2005

National Sickle Cell Awareness Month

FOR INFORMATION ON ACTIVITES, PLEASE CALL (718) 240-5904

Summer Camp - 2005

Double "H" Hole in the Woods Ranch ~ Camp Was a Blast

Every year patients from the Pediatric Hematology and Oncology Division of Brookdale Hospital attend a week long camp at Lake Luzerne. The camp provides a great get-a-way for children who have a chronic illness. This year, Parent Advocated, Hedy Stewart and 23 kids attended the camp from July 6th to 11th. Ms. Stewart has accompanied the children for many years, but it was my first time taking our kids to camp and while some of them were new attendees like me, others were on their third or fourth visit.

I was a little worried about keeping track of all the youngsters we were taking to camp, "which hosts over 100 children per session", but my worries came to an end after arriving at camp, and over 20 camp counselors met and greeted us. From that point on, the counselors did all the work.

I was assigned, as a Volunteer, to a group of 10 campers called the "Bobcats". I was now officially part of the camp. Many parents were worried about their child receiving medication, well they needn't have, the nurses found the campers wherever they were on the camp grounds.

Camper on horseback

Campers eagerly await bus' departure from Brookdale

(Summer Camp 2005 - continued)

And, there was very little time for the campers to miss home. Their daily schedule of activities was full; from 8am breakfast, to 10pm lights out. The activities ranged from rope climbing to swimming, arts and crafts to horseback riding.

I think that the most enjoyable part of the camp was the talent show, held on the last night when all the children had their moment of stardom on stage. This year, one of our own teens was the show's MC , and she did a fantastic job.

I am sure that all the kids who attended camp this year, not only had a great time and made lots of new friends, but are sure to return next year. If your child has not attended camp yet, I recommend that you sign them up for an unforgettable experience.

Tricia Cheeks, Program Assistant

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
MRS. HYACINTH GAYLE & STAFF
MAKE-A-WISH FOUNDATION
PEDIATRIC FLOOR
BROOKLYN KINGS COUNTY LIONS, INC.