Sickle Care: The Comprehensive Sickle Cell Program at Brookdale

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THE SICKLE STAR

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The Holidays are Here

Many of us look forward to December because we engage in numerous activities with loved ones, friends and colleagues. Many of these activities are rooted in our various family values and cultural traditions and despite the fact that we practice varying faiths, it is a wonderful time to come together to celebrate our respective rich cultural traditions.

At this time of year, we look around and we see Christmas trees, holiday lights and decorations and by mid-December, many homes will be decorated with all the symbols that have come to be associated with Christmas; what does it all mean?

We have listed a few of the holidays that are celebrated in our community and around the world.

Christmas - Most Christians observe December 25, to celebrate the birth of Christ. Many attend Christmas Eve and Christmas Day services. For many families it is a time of getting together for good food, fun and reflection. They also come together to exchange gifts. These gifts are symbolic of the gifts the Wise Men brought to the newborn Messiah, in Bethlehem. Families often have their own traditions, especially, concerning when and how gifts are exchanged and what foods are prepared and served. Jehovah's Witnesses and members of the Church of Christ are Christians who do not celebrate the Christmas Holiday. It is ok to wish someone who celebrates Christmas, "Merry Christmas!"

Hanukkah - is often misunderstood as the "Jewish Christmas" since it occurs in December. However, Hanukkah is the story of the struggle of Jews for freedom. This eight day, "Festival of Lights" commemorates the number of days a limited amount of consecrated oil lasted. Hanukkah is a joyful time of lighting one candle in the "menorah" (candle holder) for each of the eight days of the celebration. Special Hebrew hymns are sung, family members exchange gifts and children play with a dreidel, a four sided top inscribed with the Hebrew words "a great miracle happened here". This year the holiday starts on December 5th and ends on December 12th. "Happy Hanukkah!"

Kwanzaa- is not a religious holiday. It is a celebration that also takes place in December, from the 26th to January 1st. It is a joyful expression of African American culture. It includes music, dancing poetry recitation, talks by guest lecturers and a feast. Kwanzaa originates from the Swahili phrase mantunda ya kwanza, meaning "First Fruits". Symbols of Kwanzaa are set upon a low table, laden with tropical fruits and vegetables. A seven branched candelabrum called a "kinara" is lit , one for each day of the celebration. Kwanzaa decorations are colored in red, green and black. The red represents the struggle and blood of ancestors; green represents the land and renewed life; and black represents the diaspora of Africans and their collective beauty. Kwanzaa observance includes storytelling and seven principles: Umoja (Unity), Kujichagulia (Self-Determination), Ujima (Collective work and responsibility), Ujamaa (Cooperative Economics), Nia (Purpose), Kuumha (Creativity) and Imani (Faith). The Kwanzaa greeting is "Happy Kwanzaa!"

What you need to Know about the "504 Plan"?

Over the past year we have provided many of our parents with information about the "504 Plan". If you need to know more about this very important program that can assist your child, please contact, Ms. Yana Pennant, our Social Worker, at 718 240– 5881. At our Kwanzaa fest we will have a speaker to address this. (See community events on back page).

If you did not get a copy of the last issues of this Newsletter See below for the things you need to know about the 504 Plan. Below are the features and guidelines for filing the 504 form with your child's school:

- A child with a disability cannot be discriminated against in a public school and is entitled to receive accommodations in school so that they can fairly participate in all school programs and activities.
- Under Sections 504, your child is entitled to receive services and accommodations. An accommodation is any kind of changes in the school or classroom structure, schedule or instructions. Services can range from dispensing medications, modified participation in gym, to the use of the school elevator.
- Speak with the school nurse or principle about the 504 plan which is a form that needs to be completed by the parent and the doctor treating your child.
- Once you have all the needed documentation submit them to the school.
- The school must respond within thirty days.

Give Blood to Fight Sickle Cell Disease–Call 1 800.933.2566

Wedding Bliss for Member of SCYO

On Saturday, December 1st, 2007, the former Ms. Anndis Stewart, wedded Mr. Clive West, at the Kingsleigh Presbyterian Church, Brooklyn, at 5:00 in the afternoon. The bride wore a classic Cinderella flowing gown. The Groom wore a Nehru styled tux. The color of the wedding was royal blue and white and indeed it was "royal". It was a great sight to see these young people in their wedding bliss.

When first seeing the couple, I did a "doubletake", I thought they looked like brother and sister. "Old Timers" say that's good luck and they are well suited to each other. We wish them many Blessings and lots of good wishes.

SICKLE CELL DISEASE ASSOCIATION OF AMERICA ANNUAL CONVENTION

This fall, Doctors, Staff and (3) Parents attended this year's **Annual Convention of the Sickle Cell Disease Association of America** (SCDAA) in Washington, DC. The successes of the Program were presented in Poster format. Below, Health Educator, Lynette Smith, MPH, is discussing the Community-Based Sickle Cell Project with conference attendee.

HOLIDAY PARTY TIME IS HERE

Our *Annual Holiday Party* is scheduled for *Thursday, December 13th 2007, from 4:00p.m to 8:00pm*. We are asking all parents, friends, and supporters to help us make this a wonderful and memorable occasion for the children.

We would like more parent participation. Last year a handful of our dedicated family members from our parent support group came out to help wrap gifts. This year we would like parents to participate by coming up with new ideas to keep the party fresh and exciting for our children.

Parents may have ideas about gift donations (all our gifts are donated), entertainment from church groups, a community group, school, or even a new theme for the party. All ideas are welcomed.

We have a lot of great activities. So come out and get your child signed up .

We encourage, all of our parents to participate in the many monthly and annual activities.

Note, the next P*arent Support group* is scheduled for ***Thursday, January 3rd at 6:00p.m.***

We are looking for ideas and parent volunteers to help make our 2008 events extra special.

SCDAA ANNUAL CONVENTION (cont from page 2)

BROOKDALE ATTENDEES WHO WENT TO THE SCDAA ANNUAL CONVENTION,NETWORKED WITH MANY NATIONAL AND INTERNATIONAL SICKLE CELL ORGANIZATIONS AND CELEBS. THERE WAS A WEALTH OF KNOWLEDGE ABOUT SICKLE CELL AND PRESENTATIONS AND WORKSHOPS EXPLORED CLINICAL, SOCIAL, EDUCATION AND OUTREACH ASPECTS OF CARING FOR AND COPING WITH SICKLE CELL DISEASE.

PROGRAM ANNOUNCEMENTS/HAPPENINGS

Parents Support Group

Meets on the first Thursday of the month. Refreshments are served. We need parents to come out. Next meeting will be Thursday, January 3rd, 2008.

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 January 4th, 2008. 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 the Department of Health-Newborn Screening Program to test parents who are uninsured and whose babies are identified with sickle/hemoglobin trait through Newborn Screening.

Parents of children diagnosed with sickle cell trait, C, or E, or disease can request to be tested.

Through this program , we have identified families at-risk for having a baby with sickle cell disease.

Know your hemoglobin type,

Get tested!!!

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

Parent's Corner

My name is Tonji Newman and I am the parent of Christopher Newman, who has SC Disease. This year I have been an active participant in the program. In February, I attended the 1st Annual Sickle Cell Research and Educational Symposium, "Transition from Pediatric to Adult Care," in Florida. This Symposium was very educational, as well as, informative.

I also attended the parent meetings, which are held on the 1st Thursday of every month. They are interesting, although I wished that more people would become involved. It is important that we as parent become informed about sickle cell, so that we can educate others and dispense some of the myths regarding the disease. As a Parent Advocate, I also spoke on sickle cell at Grand Army Plaza at a health seminar.

I was nervous but everything went well. I was asked a lot of questions and I was able to give the correct answers. So again, I just want to say parents should get more involved.

BLOOD SAVES LIVES

Brookdale held its Annual Blood Drive on September 28, 2007, in Brookdale Hospital's Alumni Hall. As many of you know children with sickle cell disease are especially at risk for having strokes. Blood transfusions have been found to be one of the most effective treatments for prevention of strokes and treating the many complications of sickle cell disease.

Well you may be asking, "What can I do?"

You can give blood. Your blood is the most important commodity for patients who need your blood type, so why not give the "gift of life" and donate a pint of blood.

Do you know your blood type?

The following is a list of the different blood types and the percentage of the population that carries that type:

O Rh-positive: 38 percent
O Rh-negative: 7 percent
A Rh-positive: 34 percent
A Rh-negative: 6 percent

B Rh-positive: 9 percent
B Rh-negative: 2 percent
AB Rh-positive: 3 percent
AB Rh-negative:1 percent*

This year we collected almost 40 pints of blood.

Community Events

CWHA & Brookdale's Community-Based Sickle Cell Project Celebrate Kwanzaa

Friday, December 28, 2007 11:00am-2:00pm

Brooklyn Public Library

Flatbush Branch

22 Linden Blvd (Cor. Flatbush Avenue), Brooklyn

The Community-Based Sickle Cell Project in partnership with Caribbean Women's Health Association, is inviting all families to attend the Annual Kwanzaa celebration. We will be celebrating the traditions of Kwanzaa and there will be food and fun and lots of fun for all, and lots of gifts for the children.

Sickle Cell Program's Annual Parents Retreat

Saturday, January l9, 2008. The retreat will be held at the Samuel & Bertha Schulman Institute

555 Rockaway Parkway - Room 206

Brooklyn, New York

Sickle Cell Program's Annual Youth Retreat

Saturday, May 10, 2008

555 Rockaway Parkway - Room 206

Brooklyn, New York

SINCERE THANKS FROM OUR FAMILIES TO YOU ALL

ZITWER FOUNDATION
CARLITOS WISH FOUNDATION
COACH TITLEY & CANARSIE HIGH FOOTBALL TEAM
KINGS COUNTY SICKLE CELL, INC.
STARLIGHT FOUNDATION
TASHA'S LIFE FOUNDATION
SICKLE CELL THALASSEMIA PATIENTS NETWORK
BROOKDALE HOSPITAL ADMINISTRATION
THE DEPARTMENT OF FOOD & NUTRITION SERVICES
KINGS COUNTY LIONS CLUB
DEPARTMENT OF RADIOLOGY
MAKE-A-WISH FOUNDATION
PEDIATRIC STAFF & FLOOR
DOUBLE "H" HOLE IN THE WOODS RANCH
ALPHA KAPPA ALPHA
JACK AND JILL OF BROOKLYN
COMMON CENTS, INC.
PHEBEANA PRE-SCHOOL
TOYS FOR TOTS