Sickle Care: The Comprehensive Sickle Cell Program at Brookdale

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THE SICKLE STAR

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What is a Parent To Do?

As schools reopen for the Fall term, parents have many concerns about their children living with sickle cell disease. Sometimes parents are unsure about what is happening with their child while that child is away from them, others have concerns about when they should seek care for their child. It is imperative that you obtain a "504 Plan"* from your child's principle or school nurse. * (See explanation top page 2)

Here are some questions which parents frequently ask our physicians. The answers will help to keep your child healthy.

- **Q.** How do I know if my child is having a crisis?

A. Listen to your child when he/she says they don't feel well. If he/she is not playing normally, this is a tell tale sign.

- **Q.** Is it ok for my child to go to school in cold weather?

A. Yes, however exposure to extreme heat or cold can allow the red blood cells to become sickle cells. So dress your child for the weather; wear warm clothing outside during cold weather and inside when in air-conditioned rooms during warm weather.

- **Q.** Should my child be on a special diet?

A. Children with sickle cell disease should take folic acid supplements daily. They should eat a well-balanced diet.

(Folic Acid and other vitamins feed our bone marrow and allow our cells to grow and make new red blood cells).

- **Q.** Can my child participate in physical education class?

A. Children with sickle cell disease should exercise regularly, but should not overexert themselves. Always talk with your physician about how much exercise is right for your child. *(When you exercise, drink plenty of fluids).*

- **Q.** What can I do if my child feels stressed by his/her school work.

A.. We cannot avoid stress altogether, but we can reduce it. A sickle cell crisis can occur as a result of stress. If your child shows signs of stress, talk to your child's teacher, talk to your child's physician or social worker.

Other Key Suggestions:

Have your child drink several glasses of water a day, especially during warm weather. Staying hydrated helps to keep the blood circulating properly. This reduces the chance that red blood cells will sickle.

Seek medical attention for your child as soon as he/she has a temperature of 101° or higher.

When in doubt, call your physician.

TO ALL OUR WONDERFUL CHILDREN ~ HAVE A GREAT YEAR!

What is the "504 Plan"?

As the parent of a child with sickle cell disease you should be aware that your child has many services available within the school system. This is largely due to the 504 civil rights law. 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.

If more information is needed about the 504 Plan, please call (718) 240-5904, to speak with the Social Worker.

Give Blood to Fight Sickle Cell Disease

1.800.933.2566

ANOTHER DVD TO BE RELEASED

The Comprehensive Pediatric Sickle Cell Program, Community-Based Sickle Cell Project is finalizing their third DVD, Sickle Cell Disease and Your Baby.

This DVD discusses sickle cell disease and associated conditions which often develop in infants and toddlers as a result of having the disease.

The aim of the DVD is to assist families in detecting some of the early signs of the onset of a crisis and to provide them with information that is useful as their newborn gets older.

Dr. Kusum Viswanathan, Director of Brookdale's Division of Pediatric Hematology/Oncology and Vice Chair of the Department of Pediatrics and several of our Brookdale families were interviewed and participated in the making of this DVD.

We wish to thank all of our families for their time, attention and participation.

This DVD will be given to families of children between the ages of birth to five years old, but will mostly be targeted to parents of newly diagnosed children. It will also be shown in our hematology office and in our weekly sickle cell clinic.

Poster Child, Janine Sharpe dons the cover of 2006 released DVD entitled; **Empowering Our Community Sickle Cell Education and Care In Brooklyn.**

FALL PEER TRAINING TO BEGIN OCTOBER

Our Fall 2007, Peer Education Training session will begin in October 2007. In Fall 2006, the Community-Based Sickle Cell Program initiated a Peer Education Training Program, working with our project partner, Brownsville Multi-Service Family Health Center, at W.A.T.C.H. High School (World Academy for Total Community Health) .

Housed within the Thomas Jefferson High, School the WATCH High School is a college prep high school which focuses on careers in the health industry. During the Spring '07 session, four students received certificates of completion.

This session was particularly rewarding as we worked with the school to institute the Peer Training as part of the newly developed Internship/Community Service Initiative, which required the students to attend, in order to get high school credit for community Service. The Community-Based Sickle Cell Project successfully completed the eight week training, "graduating" four students who had an opportunity to work in the community health center during the summer. Spring session student Cal stated, "I wasn't interested at first, but it got really interesting to learn about sickle cell".

Students prepare for their final presentations

Student Cal conducts final presentation before her peers.

ANNUAL HOILDAY PARTY

Our *Annual Holiday Party* is scheduled for *Thursday, December 13th 2007, from 4:00p.m to 7:00pm*. 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 so come and share them with us.

This year we would like to hold a talent show in which the children can participate. The children can showcase their talents in a caring and loving environment. So get your child signed up for the talent show!

Please call, or better still come to the next *parent support group* with your ideas for the holiday party. Our next group is scheduled for ***Thursday, October 4th at 6:00p.m.***

We are looking for ideas and parent volunteers to help keep this event *exhilarating!!!*

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

SICKLE CELL AWARENESS MONTH EVENTS

- **Thursday, September 6, 2007, Monthly Parent's Support Group, Room 346 CHC.**
- **Friday, September 7, 2007, Youth Support Group, Room 346 CHC.**
- **September 7, 14, 28th Outreach/Tabling**
  (Fridays 10:00am - 2:00pm) – Brookdale Lobby
- **September 10, 17, 24, and 28th 10am - 2pm**
  (Mondays 10:00am - 2:00pm) - Brookdale Lobby
- **Friday, September 14, 2007, Sickle Cell Grand Rounds**
- **September 15, SCTPN Walk-a-Thon, Central Park, NYC**
- **National Sickle Cell Disease Association of America Convention - September 17-22, 2007, in Washington, D.C.**
- **Friday, September 21, 2007, 10am to 4:30pm Parent Advocate speaking at CWHA's Infant Mortality & Prenatal Care Awareness & Services Event - Brooklyn Public Library**
- ***Friday, September 28, 2007, Brookdale Blood Drive***
- **Saturday, September 29, 2007, Kings County Sickle Cell Inc., Walk-a-Thon, Canarsie Park, Brooklyn, New York**

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, October 4th, 2007.

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 October 5, 2007. 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?

Presenter at Annual Parent Retreat receives top honors for her craft

The winner of the 2007 Doll & Teddy Bear Expo Hotel Package was Mrs. Pearl Paul from Brooklyn, NY. You might remember that Mrs. Paul was one of our presenters at this year's Parent's Retreat. She uses her talents tfor enjoyment and to create personal income.

Our parents enjoyed Mrs. Paul's presentation so much they requested that she do a follow up session with our monthly support group. This request was granted at February's support group meeting. Mrs. Pearl said she was very grateful for the opportunity to work with the parents of the sickle cell program.

Mrs. Paul is the inspiration behind the dolls pictured below. It is her passion and desire to showcase her craft that led her children to the *DOLLS* magazine, Doll & Teddy Bear Expo and the entrance into this sweepstakes.
Mrs. Paul who believes that persistence pays says, "why not use your talents to create extra income for yourself and your family".

Mrs. Paul teaches her craft to attendees at

A proud Mrs. Paul, winner of the 2007

Winning Doll on view, created by Mrs. Pearl

BLOOD SAVES LIVES

Brookdale will hold its 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*

Hope you will donate on September 28th, 2007

Community Events

Infant Mortality & Prenatal Care Awareness & Services Event

September 21, 2007 10:00am-4:00pm
Grand Army Plaza Library, 2nd floor meeting room
10 Grand Army Plaza, corner of Eastern Parkway & Flatbush Avenue, Brooklyn
The Brooklyn Public Library, in partnership with the Caribbean Women's Health Association, is inviting pregnant women and new moms for interactive sessions on prenatal care, breast health, nutrition, **sickle cell** and more. There will be presentations on infant mortality and ways to avoid infant death, as well as information and other resources. HIV testing and consultations will be provided. For more information contact Maxine Cooper at 718-230-2477 or email m.cooper@brooklynpubliclibrary.org

(Our very own Parent Advocate, Tonji Newman will be providing sickle cell information)

Jamaica Nurses Association Health Fair

September 22, 2007 12:00noon– 4:00pm
Unity East Church Center
1901 Beverly Road Brooklyn
For more information call Donareen Denny at 718-221-6186.

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
PEDIATRIC STAFF
MAKE-A-WISH FOUNDATION
PEDIATRIC FLOOR
DOUBLE "H" HOLE IN THE WOODS RANCH
ALPHA KAPPA ALPHA
JACK AND JILL OF BROOKLYN
TOYS FOR TOTS
COMMON CENTS, INC.
PHEBEANA PRE-SCHOOL