Sickle Care: The Comprehensive Sickle Cell Program at Brookdale

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THE SICKLE STAR

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Pain Common With Sickle Cell Disease

We thought this was and important article to reprint because it speaks to the "pain" experience of many individuals who have sickle cell disease. This article appeared on Jan. 14, 2008, in the *Annals of Internal Medicine*.

"Pain is "the rule rather than exception" among adults with sickle cell disease, researchers report. Sickle cell disease is an inherited condition in which certain red blood cells become crescent-shaped (sickled). That makes it hard for those cells to pass through narrow blood vessels, which deprives tissue of oxygen and causes pain.

Experts at the University of Virginia and Virginia Commonwealth University studied 232 people age 16 and older (average age: 32) with sickle cell disease. For six months, the patients kept daily diaries about their sickle cell pain. Those diaries show that:

- 29% of the patients reported sickle cell pain nearly every day.
- 54% reported pain on more than half of the days.
- Only 14% rarely reported pain.
- Average pain intensity was in the middle of the study's pain scale.

The patients often didn't go see a doctor about their sickle cell pain, handling it at home instead. "Our results are both surprising and striking," wrote Virginia Commonwealth University's Wally Smith, MD, and colleagues. "Pain in adults with sickle cell disease is far more prevalent and severe than previous studies have portrayed, and it is mostly managed at home. "Smith's team concludes that sickle cell disease should be recognized as a source of chronic pain. The study appears in the *Annals of Internal Medicine*.

Smith, W. *Annals of Internal Medicine*, Jan. 15, 2008; vol 148: pp 94-101.

NIH Conference on Sickle cell disease and Hydroxyurea

The NIH held a Consensus Development Conference on Hydroxyurea Treatment for Sickle Cell Disease on February 25-27, 2008.

The objective was to provide health care providers, patients, and the general public with a responsible assessment of currently available data on hydroxyurea treatment for sickle cell disease.

A non-DHHS, non-advocate 14-member panel representing the fields of internal medicine, family practice, hematology, oncology, pediatrics, obstetrics, nursing, pediatric nursing, social work, pharmacology, pharmacokinetics, and pain research, mental health, epidemiology, biostatistics, public health, and health systems research, in addition to a public representative heard 22 presentations from experts in the field.

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PARENT'S PAGE

My name is Leslene O'Meally-Whyte. I am the mother of Jordana Whyte she was diagnosed with Sickle Cell Disease.

I'm sharing my story because I am confident that the challenges which I have and continue to face will motivate, inspire, encourage or provoke someone to view the challenges in their individual life differently.

One month after marriage I was diagnosed with a brain tumor. Eight months after being diagnosed with a brain tumor, pregnant and confused, I asked GOD a few of the big "W's".

Why was this happening? What did I do to deserve this? What good is going to come out of this? What am I supposed to do now? Why did you choose this path for my life? I was just full of questions! After having my "moment" I decided to shut up for a while and these words came to me…

WORLDWIND……ARISE

(Written 5-14-99)

Tossed to and fro, uncertain of which way to go
Though you try, all seems to fail
Just when it seems to be coming together, the wind beneath you sweeps you off your feet and tosses you around

But you know, you must rise up from where you lay
Even though your body aches and you feel you can't go on
*You are reminded that……**Greater is He that is within you the he that is in the world***
So, you stagger to stand - your knees shake and your head hurts
I say unto you: Arise my child my strength is made perfect in weakness
Arise and stand, I have already placed within you all you need to stand

To stand against the enemy of your soul
Lo, my child I am with you always
I will never leave you or forsake you
For a small moment my child, I have turned my back against you

But remember, with great power I will raise thee up
Your enemies shall be your footstool
I have not forgotten you
I will be with you always

My sons, my daughters, my children, I know what lies ahead.
I know what surrounds you
But, you must stand!

You must stand for all who will come after you
Those who look to you for strength
There is work for you to do - Listen to my voice

My darlings, all you need is already given to you
I have overcome so, you will overcome
Trust in me. My word is true, my word is life

Arise my children and stand - arise my servant, there is greatness in you
You are an over-comer, you are a conqueror.

In July of 2000, still diagnosed with a brain tumor I gave birth to my third child. My first child was before all the major drama started, the second one was during the confusion and now my child is diagnosed with Sickle Cell Disease.

Why is all this drama happening!

I haven't yet even begin to deal my personal issue and now this! As parents of children diagnosed with Sickle Cell you know the drama you face daily with school absences, pain crises, hospitalizations, ER's, guilt, the list is endless.

Bottom line is this, you are able to overcome. You are able to endure more than you think! It could be worst! In everything give thanks! This too will pass!

You are an over-comer, you are a conqueror!

Publishers Note:

Mrs. Leslene O'Meally-Whyte is a dedicated member of our parent support group. She was selected as a scholarship recipient for the Sickle Cell Disease Association of America's Annual Convention in 2007.

Sickle Cell Disease and Mental Health

On March 6th, 2008, the Comprehensive Sickle Cell Program's monthly support group discussed the very important topic of sickle cell disease and mental health. The speaker was Hatel Patel. The main question was, "How Do We Address the Mental Health Issues of Children with Chronic Health Issues?" The main points addressed were as follows:

- **Recognizing that the symptoms of the disease does not only impact our children physically but also psychologically.**
- **Repetitive hospitalizations have an impact on the development of social/educational/peer skills that children need to learn.**
- **Changes in behavior, i.e., child does not like things that they used to like before, refuses to socialize, strains relationships with loved ones.**

These are all indicative of some issue or problem that may arise.

Ms. Patel also noted that she learned a lot from meeting with the parents. She stated, "I think it helped open up my mind to the needs of the parents who have children with sickle cell disease".

Double "H" Hole in the Woods Ranch Summer Camp 2008

It's time to get your application in for Summer Camp 2008. Patients ages 6 through 16 can attend this camp, seats fill up fast so come in and sign up early.

Camp dates are Thursday, July 3, through Tuesday, July 8th, 2008, during session 3.

Patients who attended last year will receive applications via mail, all new attendees can pick up forms in the office (Room 346).

Deadline for all applications is Tuesday, April 15th, 2008.

Our kids are eager for camp - parents make it happen!

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, May 1st, 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 May 2nd, 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.

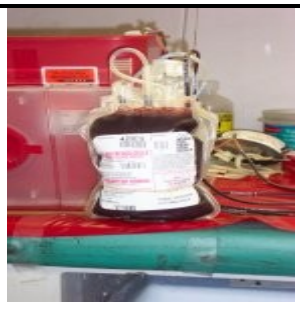
Parents of children diagnosed with sickle cell trait, C, or E, or disease can request to be tested.

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?



NIH Conference on Sickle cell disease and Hydroxyurea (cont'd)

CONCLUSIONS (Partial list): Efficacy of hydroxyurea: Strong evidence is found in support of the efficacy of hydroxyurea use in adults. Although the evidence for efficacy of hydroxyurea treatment for children is not as strong, the emerging data are supportive.

Effectiveness of hydroxyurea is hard to determine because of the lack of a precise estimate of the number of people who have sickle cell disease in the United States and the number of people actually receiving hydroxyurea. The data currently available are reassuring with respect to the **risks of both short- and long-term** harms of hydroxyurea treatment.

Patient and parent/family/caregiver barriers include: Fears about cancer, birth defects, infertility, and uncertainty of other potential long-term risks; Lack of knowledge of hydroxyurea as a therapeutic option for sickle cell disease. Provider barriers include: Limited number of physicians who have expertise in the use of hydroxyurea for sickle cell disease; Provider bias and negative attitudes toward patients who have sickle cell disease and their treatment; Lack of clarity in hydroxyurea treatment regimens and undertreatment. System barriers include: Financing: lack of insurance and coverage; For the complete draft statement, please visit http://consensus.nih.gov/.

Community Events (cont'd)

Save the Date - May 2, 2008 - Sickle cell Symposium, sponsored by New York Methodist Hospital and the Sickle Cell Thalassemia Patient's Network.

BLOOD SAVES LIVES

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*

Last blood drive we collected almost 40 pints of blood.

Community Events

Pediatric Hamatology/Oncology

Cpm[reensive Pediatric Sickle Cell Program

Community-Based Sickle Cell Project

Will host a half day seminar, From Awareness to Solutions-Management of Sickle Cell Disease: Hydroxyuea and Pain Management & and other Aspects of Management of this Disease. Friday, April 11, 2008 8:30pm-12:00pm

Brookdale's Alumni Hall –555 Rockaway Parkway,

Brooklyn, New York

Speakers

Kwaku Ohene-Frempong, MD

Paul Swerdlow, MD

Sickle Cell Program's Annual Youth Retreat

Saturday, May 10th, 2008. The retreat will be held at the Samuel & Bertha Schulman Institute

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