



THE SICKLE STAR

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Faces of Happiness — Despite!!! Two thousand and four was a challenging year for many of our children and parents. However we made it through to another year and when we reflect on our blessings, we know we have a lot for which to be thankful. Just look at these faces of happiness....



SENATORS MOVE CORD BLOOD LEGISLATION FORWARD

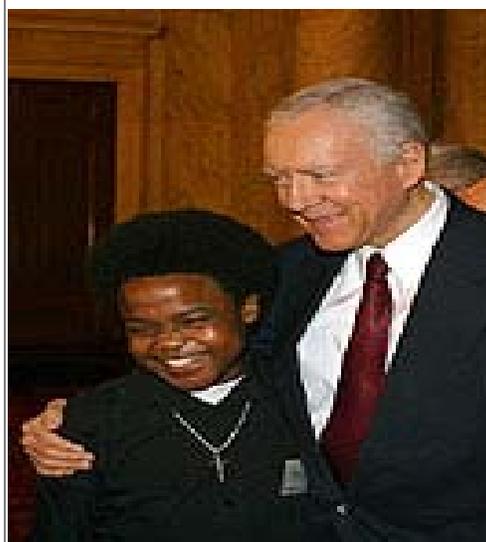
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Senator Orrin G. Hatch (R-UT), right, greets Cord Blood recipient Keone Penn, 18, at a Senate briefing to urge passage of the Cord Blood Stem Cell Act of 2005 (S681), Mon., April 4, 2005, on the Hill in Washington, D.C. Penn is the first patient to be cured of sickle cell disease with a cord blood transplant from an unrelated donor. The bill would provide federal support for a substantial increase in the inventory of cord blood units available for patients in need of a blood stem cell transplant.

(Robin Weiner/U.S. Newswire)



National Cord Blood Program Director Pablo Rubinstein, M.D., right, chats with cord blood recipient Keone Penn, 18, while cord blood recipient Stephen Sprague, center, looks on at a Senate briefing to urge passage of the Cord Blood Stem Cell Act of 2005 (S681). Penn is the first patient to be cured of sickle cell disease with a cord blood transplant from an unrelated donor. Sprague was one of the first adults treated with cord blood for leukemia. We look forward to the passing of this bill that will enable cord blood units to be available for patients in need of a blood stem cell transplant. (Robin Weiner/U.S. Newswire)

PLEASE SUPPORT
 SICKLE CELL AWARENESS
 BUY U.S. POSTAGE STAMP
 NOW AVAILABLE



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

Give Blood to Fight Sickle Cell Disease
 1.800.933.2566



BLOOD DRIVE COLLABORATION

During National Black History Month, what better way to show your love to members of your community who have sickle cell than to give the gift of life?

On February 23rd, 2005, the Community-Based Sickle Cell Project collaborated with Bridge Street AWME Church to conduct the church's annual blood drive, an event that, over the past three years, has become a part of the church's anniversary celebrations. We would like to thank Bridge Street Church, all auxiliaries, members and surrounding community that supported this event. We also wish to thank Brooklyn/Staten Island Blood Service whose staff were impeccable.

You may not be aware that there is a large disparity between compatible blood required by patients who live with sickle cell disease and the blood that is collected from donors in New York and surrounding areas. According to New York Blood Center, only 8-9% of blood donors in the region are African American as compared to more than 27% of the population of New York City. We need to increase the number of African Americans who are regular blood donors, so that there is no scarcity of compatible antigen-matched blood for patients with sickle cell disease and other alloimmunized patients.



Picture of the Sign



One Pint of Blood



Donor and Coordinator Bus-Mobile

WHY I GAVE BLOOD... FALLON E.

There are many different reasons why people give blood. I gave blood as a present for my friend who passed away last April. He was only twenty-three years old and died from complications due to sickle-cell anemia. I wish I had even a droplet of his strength. He often told me that he never had a day without pain, I could never imagine that. He thought me so much about strength and control that I felt that I had to find something that I could do for him. Giving blood was the best gift that I could every give... I am just very sad that it took his death for me to find that strength. It is now my goal to try to give blood as often as my body will allow. I gave blood for the first time on February 27th, two days after the birthday that I used to share with this close friend. I cannot lie and say that it was not scary; I was very scared. My friend's memory gave me the strength that I needed to get through the experience. I could not believe that something that I thought would be so scary would give me so much happiness. Knowing that my blood could help to alleviate someone's pain and extend someone's life made me feel great. When you give blood you give the gift of life. My friend gave me a new look on life and now I must pay it forward. This is why I give blood.

WELCOME TO THE DIVISION

We are proud to welcome Tricia Cheeks the Division of Pediatric Hematology and Oncology. Ms. Cheeks joined the division in March 2005, and assume the duties of former Program Assistant Sean Harford who moved on the Department of Surgery.

UPCOMING EVENTS

EMPOWERED WOMEN'S CONFERENCE

On Saturday, April 16th, our very own Nurse Coordinator, Lynette Hinds, R.N.C. will be presenting at the Plenary session of the Empowered Women's Conference - A collaborative event between the Women's Center of Medgar Evers College and The Women's Ministry at Bridge Street AWME Church. This event is being co-sponsored by the Community-Based Sickle Cell Project, and will provide Sickle Cell education and information, along with a host of workshops, health screenings, financial and social services. Don't miss this Empowered Women's Conference, on April 16th, 2005, at Medgar Evers College, 1650 Bedford Avenue, Brooklyn, New York.

VOCATIONAL/CAREER DAY 2005

On Saturday, May 21, 2005, from 9:30am to 2:30pm, the Division of Pediatric Hematology/Oncology will be holding its annual Vocational/Career Day. Last year we hosted fourteen speakers, in varied professions, including an attorney for MTV, Director of a Physicians Assistants program, a Fashion Consultant, an Occupational Therapist and professionals from several other interesting and rewarding fields. Please encourage your patients/children/youth to attend this day of career resources.

INSTITUTE OF MEDICINE RECOGNIZES THE NEED FOR A NATIONAL SYSTEM FOR CORD BLOOD COLLECTION SYSTEM:

In a recent press release IOM stated that the Blood from umbilical cords—a byproduct of normal childbirth—is a good source of potentially life-saving stem cells, called hematopoietic progenitor cells (HPCs), the type of stem cells also found in bone marrow and mobilized peripheral blood that give rise to various kinds of blood cells.

Transplants of these stem cells have saved the lives of roughly 20,000 Americans with leukemia, lymphoma, sickle cell anemia, and several other illnesses in recent years. However, thousands of patients who might benefit from a transplant die every year waiting for a match. Although 22 public banks have been established in the United States to collect, store, and distribute donated cord blood containing these cells, these banks operate without any centralized coordination.

Recognizing the need for a national system for the collection, distribution, and use of cord blood, the U.S. Congress asked the Institute of Medicine to review the options for such a system and to make recommendations on the ideal structure of a national program. The committee recommended that the U.S. Department of Health and Human Services should establish a new National Cord Blood Policy Board to set rules for the banking and use of lifesaving stem cells derived from donated umbilical cord blood. The department's Health Resources and Services Administration also should call for proposals to identify an organization that would manage daily operations of cord blood banking and allocation nationwide.

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. Next meeting will be May 5th, 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. Refreshments are served. For more information please call 718.240.5904.

Free Trait Testing for Uninsured Parents

Through our partnership efforts with Department of Health Newborn Screening Program and collaboration with Interfaith Medical Center, S.U.N.Y Downstate Medical Center and Kings County Hospital Center, we continue to test parents who are uninsured and whose babies were identified with sickle/hemoglobin trait through Newborn Screening.

Participants request to be tested. We have a targeted goal of 100 parents for the year and have already tested 2/3 of that number.

Through this program, we have identified risk factors for four families as we continue to increase awareness of Sickle Cell in the community.

*IOM Info:
Institute of Medicine
500 Fifth Street NW
Washington DC 20001

STROKE PREVENTION: IMPORTANCE OF TCD (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.

Save the Date

May 21, 2005

YOUTH 11-21

**Please Support
Vocational/Career
Day for Youth**

FOR MORE INFORMATION,
PLEASE CALL
(718) 240-5904

YOUTH AND ACTIVITIES 2005 WORKING WITH OUR YOUTH

Summer Camp - 2005

Double "H" Hole in the Woods Ranch

Parents and families please take note that our 2005 Camp week is scheduled for Wednesday, July 6th through Monday, July 11th. Each year our kids have a week of fun in a safe and caring environment at Lake Luzerne, NY.

Each year our kids have an awesome time. They participate in activities that include arts and crafts, ropes courses, fishing, swimming in heated pools, basketball, dodge ball, talent shows, dances, and camp outs under the stars.

The staff at Double "H" Hole in the Woods Ranch are always phenomenal with the children and we wish to thank them for all of their continued efforts in caring for children with special needs. If you have not signed up your child, you still have time... Don't miss it ...Applications are **due** by **April 15, 2005**.

Check it out for yourself, www.doubleranch.org



2004— Brookdale & Hole in the Woods Ranch Staff

YES! THERE IS HOPE FOR SICKLE CELL PATIENTS... (CONT FROM PAGE 1)

KEONE PENN SPEAKS TO CONGRESS
Eighteen year old Keone Penn, from the city of Atlanta recently spoke before Congress. He credited stem cells that are found in the umbilical cord blood with changing his life. "Stem cells saved my life." ***"Believe me, as a teenager, being in the hospital more times than you can count is not a way to live your life," said Penn,*** who is recent high school graduate. Cord blood stem cell transplants cured Penn's sickle cell disease, according to a Scripps Howard news service report. Lawmakers will introduce the Cord Blood Act "to establish a National Cord Blood Stem Cell Bank network to prepare, store and distribute human umbilical cord blood".

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.
EXECUTIVE OFFICES BROOKDALE HOSPITAL
ADMINISTRATION
THE DEPARTMENT OF FOOD & NUTRITION SERVICES
MRS. HYACINTH GAYLE & STAFF
P.S./I.S. 41 PUBLIC SCHOOL HELPER SOCIETY
PEDIATRIC FLOOR