

THE SICKLE STAR

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New Postage Stamp — Save the date

The new Sickle Cell Awareness postage stamp became available at your local Post Office on September 29th, 2004, during Sickle Cell Awareness Month. The stamp will bring awareness and raise public consciousness of this disease. In order to get the word out you need to **Request** and **Purchase** this new stamp. It's often said that our local Postal Services Centers "don't carry our stamps", but the ball is in your court, we live in a world of supply and demand.

People of all races should be screened to determine if they are carriers of sickle cell trait, or if they have sickle cell disease.

Advisory Board

- Kusum Viswanathan, MD
- Donna Boruchov, MD
- Lynette Hinds, RNC
- Verna D. Ademu-John, MS
- Suzette Boyce
- Lynette Smith
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Brookdale University Hospital and Medical Center

Provider Seminar - The Time is Now

Earlier this year the Community Based Sickle Cell Project at Brookdale, in Partnership with S.U.N.Y. Downstate Medical Center, Kings County Hospital Center, Interfaith Medical Center, Caribbean Women's Health Association, Inc., Brooklyn Perinatal Network, Inc. and The Division of Pediatric Hematology/Oncology & The Department of Medicine at Brookdale Hospital presented **The Time is Now-A Look At Emerging Issues in Management of Sickle Cell Disease.** At this seminar health care professionals engaged in dialogues about the advancements in the care and treatment of Sickle Cell Disease. **Kusum Viswanathan, MD** Director, Pediatric Hem/Onc & Sickle Cell Program—Brookdale Hospital & Medical Center, presented the history of Sickle Cell Disease and the goals of the Community Based Sickle Cell Project, **Bertram Lubin, MD** Adjunct Clinical Professor of Pediatrics President, Director of Medical Research Children's Hospital Oakland Research Institute presented invaluable information on Cord Blood banking & transplantation. **Peter Gillette, MD** Director, Comprehensive Adult Sickle Cell Program SUNY Downstate Medical Center discussed the Management of the Adult Patient, while **Samir K. Ballas, MD** Professor of Medicine

and Pediatrics, Director of the Blood Bank, Director, Cardeza Foundation Sickle Cell Center, Thomas Jefferson University Hospital provided insight to Pain Manage-



The Speakers and Organizers of our 2004 Providers Seminar



Audience listens intently at the 2004 Providers Conference

U.S. POSTAL SERVICE
HIGHLIGHTS

SICKLE CELL DISEASE

WITH NEW

POSTAGE STAMP

NOW AVAILABLE



New Postage Stamp (cont'd)

Give your STAMP of approval for the search for a universal cure and better treatment.. This historic issuance will bring renewed attention to a global health care phenomenon that is often forgotten.

The US Postal Service, Interfaith Medical Center & the Community-Based Sickle Cell Project will be hosting the Brooklyn unveiling of the United States Postal "Sickle Cell Awareness Stamp" on Monday, December 6th, 200, at 1545 Atlantic Avenue, Brooklyn, New York.

Sickle Cell Awareness, Blood Donations & The Faith-Based Community

Sickle cell awareness is a concept that has been promoted since the inception of this program over two years ago. During the month of February, which marks the Anniversary of one of our local churches, September, the Comprehensive Sickle Cell Program, Community-Based Sickle Cell Project observed Sickle Cell Awareness Month with collaborative activities. Outreach and Education sessions took place on Fridays, in Brookdale's lobby. Pediatric Hematology and Oncology, PCAP, OB/GYN Department, Dental, Live Light, Live Right Program, worked together to increase awareness of Sickle Cell disease, as well as highlight their respective programs and services. Program Staff conducted Sickle

Cell work-shops, tablings, and showed videos on Sickle Cell Disease, at Brookdale Family Care Cen-



Sickle Cell Awareness Month Outreach & Education Activities

ters, and at local schools.

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



Presentation at Plenary Session



Conference attendees view Project's Poster Board

PRESENTATIONS AT THE NATIONAL SCDAACONVENTION

Brookdale's Comprehensive Sickle Cell Program Director, Kusum Viswanathan, M.D. & Community-Based Sickle Cell Project, Program Coordinator, Verna DuBerry Ademu-John conducted two oral presentations at simultaneous scientific sessions and at the plenary session of the 32nd Annual Convention of the Sickle Cell Disease Association of America. Held in Atlanta, Georgia, this year's convention entitled, "Living with Sickle Cell Disease: Overcoming Obstacles, Maximizing Opportunities, attracted National and International attendance. It also provided an opportunity for all 17 Grantees to showcase their hard work through a Poster Session.

LETTER CORNER

On Being a Volunteer for Pediatric Hematology and Oncology

Working for this department was going to be an enriching and fun experience from day one. When I arrived, it was as though I stepped out of Brookdale. Everyone greeted me with a warm welcome and I felt comfortable.

From this experience, I came to enjoy the company of everyone in the staff. Mr. Sean Harford was extremely funny and added to the bright atmosphere of the office. Dr. Viswanathan was kind to me brought in delicious treats from home. Dr. Boruchov was very delightful and funny and always shared her anecdotes with the office. Ms. Verna DuBerry Ademu-John was a strong and evident force in my stay there. She contributed to broadening my knowledge about sickle cell disease, trait and other hematological disorders. My mentor, Ms. Lynette Hinds, RNC, always gave me wisdom about following my dreams to be a lawyer. She always told me what I do there would carry over into many jobs. Ms. Christine Rogers made me have pride in the work that I did and enjoy going to work everyday. Danielle Davis showed me that despite the odds you can beat them and become what you want to be. Despite having sickle cell herself, she is like every other sixteen-year-old and is excelling in High School and is graduating next year.

Being in the office left me with a great feeling, to see that everyone there was touching children's lives and making dreams come true. For example, for the older kids, they went to see a taping of 106 & Park, in which I had the opportunity to participate. For the younger kids, they got to go to camp, accompanied by Mr. Harford. It seems to make everyone see the good of a situation that is not always so great.

Working for the Department of Pediatric Hematology and Oncology gave me a new respect for life. I saw many kids come in in pain but when they met the staff, it was as though the pain melted away. I felt great about the good the team was doing and I am proud that I was apart of it.

Cherise Takeyma Ahay, Summer Volunteer

Dear Members of the Sickle Cell Program

I want to congratulate you on an excellent seminar. I hope my presentation on cord blood banking and transplantation in sickle cell anemia and thalassemia, stimulates staff to consider this option for a cure. We are very interested in transplanting appropriate patients who have insurance coverage for this procedure and would be willing to accommodate them at facilities in and near our hospital, during the course of the procedure. If a circumstance arises that you feel would be appropriate for such consideration, please let me know. Given our interest, and expertise in sickle cell anemia and transplantation, I hope you give serious thought to this option.

I would appreciate having this letter distributed to all participants in your program.

Yours truly,

Bert Lubin, M.D.

Director of Medical Research Children's Hospital Oakland Research Institute

Community Pediatric Residents Corner

At the outset I thank Ms. Verna Ademu-John, for giving me an opportunity to participate in the Community Based Sickle Cell Outreach program held at the BFCC, New Lots Clinic.

After a slight delay in starting up, we got rolling with a gradual trickle of people stopping by and being inquisitive about the handouts that were on offer on our table. One particular instance of a college student telling me about the "good sickle cell disease" [sickle cell trait] she had, enlightened me of the common names among lay people. I explained to her about the good and the bad components of the disease and counseled her of the possibility of prenatal screening in the future. My commitment towards my residency [on call duty], made me leave the program a bit early. Overall, it was a nice experience with a carnival atmosphere, free popcorn and nice music - a good opportunity to spend quality time while learning about the community in which I am working.

Issai Vanan, M.D.



**Cherise Takeyma Ahay,
Summer Volunteer**



**Bert Lubin, M.D.
Children's Hospital Oakland**

NEWS

Senators Talent & Schumer Sickle Cell Disease Bill Becomes Law

Friday October 22, 2004 - President Bush signed the American Jobs Creation Act (H.R. 4520), which contains the sickle cell amendment, into law . For more information see <http://www.scinfo.org/news.htm>



Program Assistant, **Sean Harford**, pictured with youth attending 106 & Park taping.



Can you say, "Hole in the Wall Gang"!

Goodbye, Note

The Division said "Good Bye, So Long," to Program Assistant, Sean Harford recently. We really enjoyed your show!!! We'll miss you Sean!

YOUTH AND ACTIVITIES 2004

WORKING WITH OUR YOUTH
BROOKDALE KIDS HAVE GREAT YEAR!

Mets Game

The Eugene Zitwer Foundation supplied families of the division with tickets to see the New York Mets play against the Montreal Expos, on Thursday, July 22nd 2004. Families received give-a-ways of towels and book bags. Although the Montreal Expos won, a fun day was had by all.



BET'S 106 and Park

Members of SCYO spent a day at the taping of **BET's 106 and Park** on Monday August 9th 2004. All thanks to the **Carlito's Wish Foundation**. The Foundation provided limousine service and an Italian lunch for those who attended the taping. The group enjoyed the energy of the host A.J. and reported that they enjoyed seeing themselves on television later that week. Again a big shout out to **Carlito's Wish Foundation** for making it happen.

Summer Camp

Double "H" Hole In the Woods Ranch,

20 of our patients and our Patient Advocate Ms. Hedy Stewart attended summer camp at **Double "H" Hole In the Woods Ranch**, at Lake Luzerne, NY.

From August 16th to the 22nd our kids had a rippin' roaring time. They participated in activities that included arts and crafts, ropes courses, fishing, swimming in heated pools, basketball, dodge ball, talent shows, dances, and camp outs under the stars,

We even got to go to Six Flags Great Escape.

The staff at Double "H" Hole in the Woods Ranch were phenomenal as always with the children and we wish to thank them for all of their efforts in caring for children with special needs.

Special Thanks to Ms. Stewart as she was an invaluable asset to the success and positive outcome of the children's experience.

Sign up the kids early for next year! Don't miss it!!!

www.doubleranch.org

MY SON ON HYDROXUREA

CATRESE HASBERRY

"MY SON, DEVIN, AGE 4 1/2 HAS SICKLE CELL DISEASE TYPE SS AND HAS BEEN ON HYDROXUREA SINCE JANUARY OF THIS YEAR. HIS LAST HOSPITALIZATION WAS IN MARCH. PRIOR TO STARTING THIS MEDICATION, HE WOULD GET HOSPITALIZED LIKE EVERY TWO TO THREE MONTHS.

THE DECISION TO START HIM ON HYDROXUREA WAS NOT AN EASY ONE. BUT AFTER DR. VISWANATHAN EXPLAINED TO ME THE INS AND THE OUTS OF IT, AND ALSO I DID EXTENSIVE RESEARCH, I DECIDED TO START HIM ON IT.

SO FAR, IT HAS BEEN A GOOD DECISION THAT I'VE MADE BECAUSE IT HAS KEPT HIM WELL, WITH LESS HOSPITAL STAYS. AFTER STARTING HYDROXUREA, DEVIN'S SPIRITS HAVE CHANGED DRAMATICALLY. I WOULD TRULY RECOMMEND HYDROXUREA TO ANYONE WHOSE CHILD HAS HAD MANY CRISSES. ULTIMATELY, IT IS UP TO THE PARENT (DO THE RESEARCH) IF THIS MEDICATION IS RIGHT FOR YOUR CHILD, THEN "GET WITH THE PROGRAM". MY EXPERIENCE WITH HYDROXUREA HAS BEEN A GREAT ONE, BUT EVERY CHILD IS DIFFERENT. I WOULD TRULY RECOMMEND THAT YOU DO RESEARCH, AND DISCUSS IT WITH YOUR DOCTOR, BEFORE STARTING ANY NEW MEDICATION WITH YOUR CHILD".

Special Thanks

Our sincere gratitude to P.S./I.S. 41, Public School Helper Society, for the Common Sense Roundtable Grant of One thousand Dollars.

Students raise funds every year through the penny harvest program that is linked to classroom and school wide learning activities.

After pennies were collected students participated in an eight week process to determine community need. The Comprehensive Sickle Cell Program was successful in receiving the grant.



**Dr. Viswanathan &
Dr. Boruchov**

WELCOME TO THE DIVISION

We are proud to welcome Donna M. Boruchov, M.D. to the Division of Pediatric Hematology and Oncology. Dr. Boruchov has been with the division since the beginning of July and has already proven to be an invaluable asset to the goals and aspirations to which the Division strives. Dr. Boruchov comes to the division from Memorial Sloan-Kettering, where she was a Postdoctoral Research Fellow. Dr. Boruchov is available through the 24 hour emergency pager..

WHO SAID WHAT ABOUT THE RECENT PROVIDER'S SEMINAR:

Participant of our Provider's Seminar had a lot to say about the seminar. Here are some of the comments noted on seminar evaluations:

"It was well worth attending." M.D.

"Program was great!" R.N.

"Excellent up to date program." M.D.

"Very Good/Informative!" M.D.

"We need more of these types of seminars." M.D.

"This was long awaited, working in the Emergency Room has afforded me many encounters with

clinicians lacking empathy for patients with Sickle Cell." R.N.

"Well put together!" Patient Advocate

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 January 6th 2005. Also look for upcoming Parent's Retreat.

Sickle Cell Youth Organization

SC-YO group meetings are held on the 1st and 3rd Friday of every month @ 4:00p.m. in the office. Refreshments will be served. For more information please call 718.240.5904.

Free Trait Testing for Uninsured Parents

Through our collaborative efforts 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. The participants are willing. With a targeted goal of 100 parents for the year. We continue to promote better awareness of Sickle Cell in the community.

Holiday Party

The Holiday Party is scheduled for Thursday, December 9th, 2004. It will be held in the employees cafeteria at 5p.m. until 9p.m.

Save the Date

Queens Sickle Cell Advocacy Network, Inc., (QSCAN) will hold its Annual Luncheon on Saturday, December 11th, 2004. This year's luncheon will be held at Antun's, 96-43 Springfield Blvd., from 11:30am to 4:00pm. This organization works tirelessly to promote awareness and raises funds for sickle cell.

Please Support this activity.

FOR MORE INFORMATION, PLEASE CALL

Ms. Gloria Rochester

(718) 712-0873

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 NET-
WORK
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

WE APPLAUD YOU!