Sickle Cell Information Center Web Site Update for August 2005

The Latest Information about Sickle Cell Disease and The Georgia Comprehensive Sickle Cell Center in Atlanta, GA at http://www.SCInfo.org

Sickle Cell Bill Funding Update 7/20/05 - Thank you for your support! The bill passed out of the Senate Appropriations Committee has $500,000 to fund our sickle cell disease law, up from approximately $200,000 from last year. Senator Talent would like to increase this amount when the bill moves for a vote on the Senate floor likely in the Fall. We will continue to keep you posted.

BACKGROUND ON THE SICKLE CELL TREATMENT ACT (in Public Law 108-357):
Sickle Cell Disease (SCD) is an inherited blood disorder that is a major health problem in the United States, primarily affecting African-Americans. This bipartisan, bicameral legislation authorizes a Health Resources and Services Administration grant for research, treatment and community outreach for SCD patients through qualifying community health centers. Last year this bill received $200,000 for grants to establish a demonstration program and a National Coordinating Center to develop systemic mechanisms for the prevention and treatment of this disease.

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The Sickle Cell Society was founded in 1979 by a group of healthcare professionals, sufferers and families affected by sickle cell in the London Borough of Brent. The Society was later established under a Memorandum of Association with the objects and powers of a charitable company and is governed under its Articles of Associations, since 1993. Under those Articles, the Society is limited by guarantee not having a share capital. Each of the members of the Society is liable to contribute £1 towards the liabilities of the Society in the event of liquidation.

The Society’s charity registration number is 1046631 and the company registration number is 2840865. The Head Office is located at 54 Station Road, London NW10 4UA.

MISSION STATEMENT - The Society’s mission is to enable and assist individuals with a Sickle Cell disorder to realize their full potential. This mission will be achieved by raising awareness through: education, the provision of welfare services and assisting in research. Click here for the full report as a word file <http://www.scinfo.org/SickleCellSoc05.doc>

Communicating with Congress: How Capitol Hill is Coping with the Surge in Citizen Advocacy - The Internet and e-mail have made it easier
and cheaper than ever before for citizens to communicate with their Members of Congress. In 2004, Congress received 200 million communications, four times more than in 1995 -- the direct result of Internet-based communications. This increased citizen participation in the legislative process has had both positive and negative effects. Nearly 80% of congressional staff surveyed believe that the Internet has made it easier for constituents to become involved in public policy. However, neither the senders nor the receivers of congressional communications have learned how to use the new tools that the Internet has provided truly effectively. http://www.cmfweb.org/cwcreport1.asp

Ohio Sickle Cell and Health Association starts email newsletter
The premier edition of Ohio Sickle Cell News was launched August 5th. This monthly newsletter will serve as a source for news and upcoming events related to SCD Programs in Ohio. Register at to http://www.ohiosicklecell.org

Woman struggles to care for sick daughter

*Publishing giant John H. Johnson passes at 87 *Publisher of Jet and Ebony had a son John H. Johnson, Jr., who died in 1981 from sickle cell anemia.

Jackson back at Duke, but it's no game
Delaware State men's basketball coach watches son undergo potentially life-saving bone marrow transplant

Resources - Educational Books
The Institute for Child Health Policy (ICHP) recently completed work on a booklet for youth and families entitled “Envisioning My Future: A Young Person’s Guide to Health Care Transition”.
ICHP also developed a set of three health care transition workbooks for youth & families; and tailored the workbooks for use by those served through CMS - Florida Children's Medical Services Program. The workbooks (for ages 12-14; 15-17; and 18+) are designed to help families and youth think about future goals, to identify things that the young person is doing currently to be independent in health care; and help figure out what needs to be done to assure that the young person's future transition from pediatric to adult-oriented health care goes smoothly.

While these workbooks can be done independently, by a young person and family, it may be best for families, youth and providers to work together to identify current strengths and needs; identify priorities; and develop and implement a plan for addressing current and future needs.

These materials are available on the health care transitions web site at: http://hctransitions.ichp.edu/resources.html

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**Articles in the Medical Literature**

August 2005


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Mohan JS, Lip GY, Bareford D, Blann AD. Platelet P-selectin and platelet mass, volume and component in sickle cell disease: Relationship to genotype. Thromb Res. 2005 Jul 26; 
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New Web Links

August

*Heath Hop Music - Rap for Health* [http://www.healthhopmusic.com/](http://www.healthhopmusic.com/) *Dr. John Clarke and Health Hop® Songs use an evidence based approach. All songs are written by Board Certified Family Physician Dr. John D. Clarke and are based on information gathered from a thorough review of literature and guidelines and recommendations set forth by organizations including the American Academy of Pediatrics, The American Academy of Family Physicians, The Center for Disease Control, American Lung Association, American Academy of Asthma Allergy and Immunology and others. There is a Sickle Cell Rap CD called You Could Feel Good” Rap song plus physician discussion on sickle cell crisis & prevention Plus many other excellent titles. See the full story at [http://www.scinfo.org/newsrap.htm](http://www.scinfo.org/newsrap.htm) . The website has sample music clips and ordering information. For more information contact Dr Clarke at email healthhopmusic@aol.com and the phone number as 718-314-6027.

* Genetic Tools: Genetics Through a Primary Care Lens [http://www.genetictools.org/](http://www.genetictools.org/), On July 11, the University of Washington will have a pre-release of Genetic Tools: Genetics Through a Primary Care Lens [http://www.genetictools.org/](http://www.genetictools.org/), a new online genetics resource for primary care faculty. Building on the demand generated by the Genetics in Primary Care Project, this web-based resource provides publicly available teaching cases, templates, and tools for use in a variety of clinical teaching settings. This project was funded in part by the Maternal and Child Health Bureau of the Health Resources and Services Administration.

Conferences and Activities of Interest to the Sickle Cell Community

Atlanta- GA activities

*September 24* Sickle Cell Night at Braves Game, Grady Sickle Cell Walk - TBA

*October 8, 2005* Sickle Cell Education Day The Loudermilk Center Downtown Atlanta - an annual event held in the fall for children with sickle cell disease and their parents and hosted by the Atlanta Sickle Cell Consortium. Simultaneous parent and child (ages 5 plus) programs will cover treatment updates, newest clinical advances and school health
issues. Door prizes, refreshments and lunch will be provided. Siblings and other family members are invited as well. Please contact Tracy Winters at 404-785-2371 or tracy.winters@choa.org.

*October 22* Anchor's Fall Fashion Show - TBA Contact for Atlanta Anchors - Children Support Network: Clarence Matthews, President - (404) 387-2870 e-mail: cmatt2976@yahoo.com Velma Rocquemore, Vice President - (770) 435-3937 e-mail: jrocq42@bellsouth.net

*August 13 - 14 LA - Celebrities Unite to "Bowl a Strike for Sickle Cell Disease"* August 13 & 14 in Los Angeles, CA. Pre-Event Fundraisers will be held in July http://press.namct.com/content/view/2268/9/

*August 29 - September 2, 2005* NIH Annual Sickle Cell Clinical Research Meetings The Natcher Conference Center (NIH Campus) - Building 45, 45 Center Drive Bethesda, Maryland 20892 http://www.rhofed.com/sickle/

For a PDF brochure and registration form click here http://www.scinfo.org/NIH905.pdf

*September 22 Chicago IL* - Multi disciplinary Approach" to the Management of Sickle Cell Disease 2005 Conference Thursday on September 22, 2005 8 A.M. - 7 P.M. at the Oak Lawn Hilton 9333 South Cicero Avenue Oak Lawn, IL 60453-2517

For More Information: Call 312-345-1100

Our program has been certified by the University of Illinois for up to 8 Category 1 CME credits. We are also applying for nursing and social worker continuing education.

*September 7 - 10, 2005* *SCDAA* 33rd Annual Convention Theme: "Strengthening Partnerships, Policies and Services" September 7 - 10, 2005 Baltimore, Maryland Renaissance Inner Harbor Hotel http://www.sicklecelldisease.org/

*September 17, 2005 New Your City, NY* - The Sickle Cell - Thalassemia Patients Network Walk for Education will be on September 17th in Central Park. For more information, please call 877-812-4216
**September 24th** *Hollywood FL* - The Memorial Healthcare System will sponsor a free community event on September 24th. Location: Martin Luther King Jr. Center
2400 Charleston Street, Hollywood, Fl. 33020
8 am: Sickle Cell Awareness Walk "Help Stamp Out Sickle Cell Disease" We will use the post office sickle cell stamp as our logo. 9 am - 2 pm: Free health fair which will include sickle cell screening, prostate cancer screening, bp screening, cholesterol screening and other health and safety information. For additional information: (954) 985-3435

* September 24, 2005 - Philadelphia, PA* - 8th Annual Walter E. Brandon Sickle Cell Disease Walkathon. This event will take place in Philadelphia on Saturday September 24, 2005 and is a major fundraiser to allow us to continue providing supportive services to, children, adolescents, adults and families affected by sickle cell disease and sickle cell trait. The walkathon is named in memory of the late Rev. Walter E. Brandon, Co-Founder of SCDDA/PDVC, who was spearheading the first annual walkathon, when he passed away on April 2, 1998 at the age of 59 from complications of sickle cell disease. For more information contact zbrandon@verizon.net

**Web site** http://www.sicklecelldisorder.com

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*Sept 20 -22 Nigeria - SICKLE CELL ANAEMIA SEMINAR* Organized by: ABIA HEALTH SYSTEM DEVELOPMENT PROJECT- In remembrance of the following: EMEKA ONYIOHA, OZUO ONYIOHA, UCHE U. MADUAKO AND OTHERS


Month: SEPTEMBER Day: 20^TH – 22^ND Year: 2005 Time: 10.00 a. m

For more information contact emekaozuouche@yahoo.com

The purpose of our seminar-workshop is to educate the public and the Sickle-Cell anemia sufferers on the importance of

* genetic guidance during marriage
* management of Sickle-Cell anemia
* alternatives and remedies
* policy formulation for legislatures and advisors

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* September 24-25, 2005 - Toronto - The National Anemia Conference (Canada) will take place in Toronto * at the Novotel Toronto Centre - 45 The Esplanade, Toronto, Ontario Canada. The National Anemia Conference
is the pre-eminent Canadian event bringing together patients, families, researchers & healthcare professionals for education and information-sharing around chronic anemia conditions.

Mission - The National Anemia Patient Conference is a meeting of patients, families, physicians, and healthcare professionals, which aims to help patients with chronic anemia to live life to their fullest potential.

We do this by:

1. Providing patients, physicians, and other healthcare professionals with information on current state-of-the-art treatments, therapies, and research studies for chronic anemia, as well as emerging technologies and therapies.
2. Supporting patient & family empowerment in areas like informed decision making, managing treatment adherence, and handling physical, social, and emotional issues.
3. Building awareness and momentum for actions that will address barriers that may currently prevent patients from achieving optimal care for chronic anemia.

Host groups are: the Anemia Institute for Research & Education; the Aplastic Anemia & Myelodysplasia Association of Canada; the Canadian Sickle Cell Society; Fanconi Research Fund of Canada; Sickle Cell Association of Ontario; and the Thalassemia Foundation of Canada. For more information, visit http://www.anemiainstitute.org/events/national_anemia_conference_september_2005

* April 8 – 12, 2006 Memphis, TN* - The 29th Annual Meeting of the National Sickle Cell Disease Program will be held in Memphis, TN, at the Peabody Hotel from April 8 – 12, 2006. The meeting is an annual event hosted by one of the ten Comprehensive Sickle Cell Centers designated by the National Institutes of Health. This year, the program will be hosted by the Comprehensive Sickle Cell Center at St. Jude Children's Research Hospital. The meeting represents a major national and international forum for research in sickle cell disease and an important venue in which scientists, clinicians, researchers, social workers, psychologists, and other healthcare professionals collaborate and interact. For more information visit us at http://www.stjude.org/sicklecellconf

If you wish to be removed from this update news, Please send an email request to aplatt@emory.edu with the email address that the newsletter was addressed to. If you know of others that would like to receive an email
update about the Sickle Cell Center Web site, have them write an email to
aplatt@emory.edu

Allan Platt PA-C
Web Site  http://www.SCInfo.org  <http://www.emory.edu/PEDS/SICKLE>
aplatt@emory.edu