Sickle Cell Information Center Web Site Update for October 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 List Serv at http://listserv.emory.edu/archives/sicklecell.html
You may now join, leave and review past newsletters on the Emory Sicklecell Listserv. This is the current method of newsletter distribution.

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Exjade(R) (deferasirox) progress - The Blood Products Advisory Committee (BPAC) of the U.S. Food and Drug Administration (FDA) has given a positive review of Exjade(R) (deferasirox) for once-daily oral treatment of adults and children with chronic iron overload due to blood transfusions. The committee unanimously recommended use of Exjade for patients who undergo repeated blood transfusions to treat certain rare, chronic blood disorders including, sickle cell disease (SCD), thalassemia, other rare anemias and myelodysplastic syndromes and may be at risk for iron overload. This recommendation will have full FDA review in November.

http://www.fdaadvisorycommittee.com/FDC/AdvisoryCommittee/Committees/Blood+Products/092905_exjade/092905_ExjadeR.htm

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Sickle Cell Disease: A Lifelong Struggle By Francis X. Owoo
http://www.thesuffolkstandard.com/feat-000010-1.php

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RFP - Exploratory and Developmental Research Grants for Investigations in Rare Diseases (R21)

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Sickle cell center opens PALMETTO FL - Growing up with sickle cell anemia, Gary T. Peterson doesn't remember his illness getting the national attention paid to conditions such as breast cancer and heart disease.

Peterson, 31, now lives in Atlanta where he gets treatment at the Georgia Comprehensive Sickle Cell Center, the first medical facility in the world dedicated to the treatment and research of sickle cell anemia.

Peterson said his income goes entirely to his medical bills, but he realizes many people with sickle cell anemia do not have that luxury of being able to work.

New educational program founded by Gary Peterson in Florida for Sickle Cell Patients [http://www.GTPsicklecell.org]

National study: New ways to prevent stroke and reduce excess iron in sickle cell anemia - Clinical trial designed to determine if hydroxyurea can replace blood transfusions and if monthly blood withdrawal can substitute for daily injections to treat iron overload, according to St. Jude in Memphis TN.


Clinical Trials -

Sickle Cell Anemia Research Study - Collection and Storage of Umbilical Cord Blood for Sickle Cell Disease - If you are pregnant and expecting a baby that may have sickle cell disease you might be interested in our research study. We are collecting umbilical cord blood from newborns that may have sickle cell disease and we are freezing the hematopoietic stem cells that are in the cord blood. See [http://patientrecruitment.nhlbi.nih.gov/sicklecell.aspx]

Sickle Cell Anemia Research Study - Stem Cell Transplant for Sickle Cell Anemia - If you (or someone you know) is between the ages of 18-65 years and have been diagnosed with sickle cell anemia, you may be eligible for a stem cell transplantation procedure at the Clinical Center of the National Institutes of Health (NIH). Under evaluation is the use of low-dose radiation and novel methods of transplant preparation and post transplant therapy to reduce the risk of graft-versus-host disease. [http://patientrecruitment.nhlbi.nih.gov/sicklecell.aspx#42]

Clinical Trials for Sickle Cell Disease - Ongoing progress of clinical trials. There are several studies underway to improve care for sickle cell patients. Check this page frequently for new opportunities to help.

Articles in the Medical Literature

September - October 2005


Serjeant GR, Hambleton I, Thame M. Fecundity and pregnancy outcome in a cohort with sickle cell-haemoglobin C disease followed from birth. BJOG. 2005 Sep;112(9):1308-14.


Naprawa JT, Bonsu BK, Goodman DG, Ranalli MA. Serum biomarkers for identifying acute chest syndrome among patients who have sickle cell disease and present to the emergency department. Pediatrics. 2005 Sep;116(3):e420-5

New Web Links

September- October

Sickle video on PBS http://www.pbs.org/wgbh/evolution/library/01/2/l_012_02.html A Mutation Story: A gene known as HbS was the center of a medical and evolutionary detective story that began in the middle 1940s in Africa. Doctors noticed that patients who had sickle cell anemia, a serious hereditary blood disease, were more likely to survive malaria, a disease which kills some 1.2 million people every year. What was puzzling was why sickle cell anemia was so prevalent in some African populations.

Health Power - A nationally unique non-profit 501(c)3 corporation committed to minority health improvement through: a.) Health Information, b.) Health Promotion, c.) Technical Advice and Assistance to Organizations, and d.) Partnerships and Networking. www.healthpowerforminorities.org

The Health Care Transition Training Program for youth and families is available on the Web at http://hctransitions.ichp.ufl.edu/ddcouncil/

Conferences and Activities of Interest to the Sickle Cell Community

Atlanta- GA activities

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. http://www.choa.org/default.aspx?id=2365

October 22 Anchor's Fall Fashion Show – 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

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

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If you wish to be removed from this update news, Please go to the Sickle Cell List Serv at http://listserv.emory.edu/archives/sicklecell.html

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