# Sickle Cell Today





#### **Conference Gets Better and Better Each Year**

"Informative, excellent program, well planned, and simply wonderful" are just a few of the 2009 conference attendees comments describing the annual sickle cell conference entitled "Practical Issues IX: Bringing Hope to Healthcare in Sickle Cell Disease". The speakers' evaluations were rated as knowledgeable and excellent. The Cecil Parker Distinguished Lectureship featured James R. Eckman, MD, Professor, Department of Internal Medicine, Division of Hematology and Medical Oncology at Emory Winship Cancer Institute and Director of the Georgia Comprehensive Sickle Cell Center, Grady Health System in Atlanta. Dr. Eckman spoke on, "Health Disparities in Sickle Cell Disease". Other conference speakers included: J. Hoxi Jones, Strategic Partnership Specialist, Texas Health and Human Services Commission-Houston; Kathy Hall, Deputy Commissioner of Program Administration, Alabama Medicaid; and Felicia Wilson, MD (pictured), Associate Professor, Department of Pediatric Medicine, Hematology/ Oncology Division,



University of South Alabama College of Medicine. Ms. Jones, a patient advocate, spoke on the value of patient empowerment and the need for the patient to assume a lead role in their care. Ms. Hall updated the audience on the current state of Alabama Medicaid and new programs that are in their early implementation phase. Dr. Wilson addressed the pros and cons of stem cell transplantation as a potential curative treatment in sickle cell disease.

The 2009 conference presented the Planning Committee with a record breaking, enthusiastic response with over one hundred registrants, which prompted the relocation of the conference for the frst time in conference planning history. Health care professionals, social workers, parents, and clients attended the 2009 half day conference. Conference participants took advantage of the opportunity to freely network and interact with the conference organizers and speakers. The conference offers the latest information on the most innovative treatment options in the management of sickle cell disease and its complications. The conference is held annually during the spring and offers continuing education credits to conference attendees. For additional information regarding future conferences or to be added to the conference mailing list, contact our offce at (251) 470-5893.

### From THE DIRECTOR'S DESK

A Changing Trend in Health Care Delivery for Adults with Sickle Cell Disease: The Need for More Primary Care Physician Involvement

One of the major goals of Healthy People 2010 is to eliminate health disparities with substantial interest given

#### What treatment should you expect?

- Immediate blood transfusion is given if the blood count is dangerously low.
- IV Fluids
- Pain medications-when needed
- Antibiotics-when needed
- Blood draws (labs)
- Frequent monitoring of vital signs

If a child experiences several episodes of splenic sequestration, current recommendation is to consider surgery to remove the spleen. However, this should be discussed with your childs' hematologist to determine what needs to be done. Sometimes for children under the age of 2 years, surgery is delayed until they reach 2 years, however, the patient will require monthly transfusion until that time. Referral to a surgeon will be done, when the decision for surgery has been determined. All surgeries should be coordinated with the hematolgist/ sickle cell physician.

Your child will be required to have the pneumococcal vaccine (PPV-23) and meningococcal vaccine at least 4-6 weeks prior to the date of surgery is to be done.

#### Important:

Prophylactic penicillin will be required to be taken twice-a-day (everyday) after surgery.

Again, we are available for any questions or concerns you may have about this or other complications that may occur. It is very important to keep regularly scheduled clinic appointments with the hematologist/Sickle Cell Doctor to discuss potential complications and their management during the visit.

#### References:

Acute splenic sequestration in young children w/ sickle cell disease/Clinical Pediatrics, Vol. 11, No. 12, 701-704 (1972), DOI: 10.1177/000992287201101214

**Sickle Cell Information Center Guidelines:** Edited by James Eckman, M.D. and Allan Platt, PA-C The role of the spleen in sickle cell disease by Lewis Hsu, M.D., Ph.D. reviewed by Laura Jana, M.D., F.A.A.P.

NEPSCC-New England Pediatric Sickle Cell Consortium

Project # MCJ-481004 and # 2H46 MC00232-02 from the Maternal and Child Health Bureau (Title V, Social Security Act). Adapted from materials by the Texas Department of Public Health Newborn Screening Program.

Although the flu vaccine is the single most effective way to protect your self against the flu; there are also some other helpful tips:

- · avoid close contact with people who are sick
- stay home when you are sick to prevent the spread of germs
- · cover your mouth and nose when coughing or sneezing
- · wash your hands with soap and water
- · avoid touching your eyes, nose or mouth

Contact your health care provider to make an appointment for your flu vaccine. Remember the earlier the better just in case there is a shortage of the vaccine.

Ardie Pack-Mabien, CRNP Clinical Nurse Practitioner

## Swine Flu vs Seasonal Influenza; What's the difference?

www.cdc.gov/h1n1flu

Swine Flu (novel H1N1) is a new influenza virus causing illness in people. In the United States, this new virus was first detected in humans in April 2009. The virus spreads from person to person in much the same way as the seasonal influenza viruses. High risk individuals include people 65 years and older, children



Non-Proft U.S. Postage PAID Mobile, AL Permit No. 506 >20003>51