Sickle Cell Today

USA Comprehensive Sickle Cell Center

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USA Comprehensive Sickle Cell Center

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Pediatric to Adult Care Transition (PACT) Program: From Ideas to Implementation

The PACT program was implemented at the University of South Alabama pediatric sickle cell clinic on January 6, 2012. The overall goal of the PACT program is to provide our clients with a comprehensive, patient-focused, healthcare delivery system that emphasizes self-management, patient-physician collaboration, and interdisciplinary care coordination. The primary objectives of the PACT program are to empower the pediatric sickle cell client thru education, improve the transition process from pediatric to adult healthcare services, and reduce health care disparities.

Initially, the program will center on establishing working relationships with pediatric sickle cell clients ranging from ages 13-19 years who receive their care in the USA pediatric sickle cell clinic. For client's ages 13-15 years, the program is intended to familiarize the client and their families with the PACT staff as well as introduce basic transition concepts. For client's ages 16-19 years, the program is designed to address life skills that are needed to more effectively transition. The ideal result is to prepare the adolescent for transitioning to adult services with little or no complications. Participation in the transition program is strictly voluntary. Transfer to adult services occurs at age 19 years.

A multidisciplinary transition team, consisting of Dr. Johnson Haynes Jr., adult care services /pulmonologist; Drs. Hamayun Imran, Felicia Wilson and A. Hafeez Siddiqui, pediatric hematologists; Ardie Pack-Mabien, CRNP; Brittany Brown RN; and Adrienne Petite MSW/ case manager with the Sickle Cell Disease Association-Mobile Chapter, has been assembled to implement the transition process. Mrs. Brittany Brown, RN serves as the Coordinator of the PACT program. In addition, local foundations such as Mobile Works and the Alabama Career Center have dedicated their services to the PACT program.

PACT services will include education and counseling to the transitioning pediatric client and their family. Areas of focus include increasing the clients' basic knowledge of sickle cell disease, treatment options, differences in services provided by Medicaid when transitioning to adult life, patient familiarization with primary care providers who care for adults in this community as well as educating clients on the adult care services available in the Sickle Cell Center. The pediatric and adult sickle cell clinics will serve as an initial point of contact for case management services, provided by the Sickle Cell Disease Association-Mobile Chapter. The Association will serve as an invaluable resource for the provision of information on educational opportunities, availability of vocational services, career development paths, scholarships, and financial-aid programs as well as family planning, community resources, and social services.

Clients will be updated on progression with the PACT program as it occurs.

"Success is where preparation and opportunity meet" - Bobby Unser.

Brittany Brown, RN PACT Coordinator

September, National Sickle Cell Awareness Month

2012 USA ANNUAL SICKLE CELL CONFERENCE

The 2012 Sickle Cell Conference, Practical Issues XII: Casting the Net II, will be held September 7-8, 2012 at the University of South Alabama Mitchell Center, Globe. **The conference has been expanded to include a full day on Friday and half day on Saturday**. Conference attendees can participate in the entire conference or choose either day. This conference features nationally and locally recognized experts in medicine, nursing, and allied health. The conference is devoted to educating healthcare professionals on current aspects of sickle cell disease treatment, related complications, and psychosocial issues.

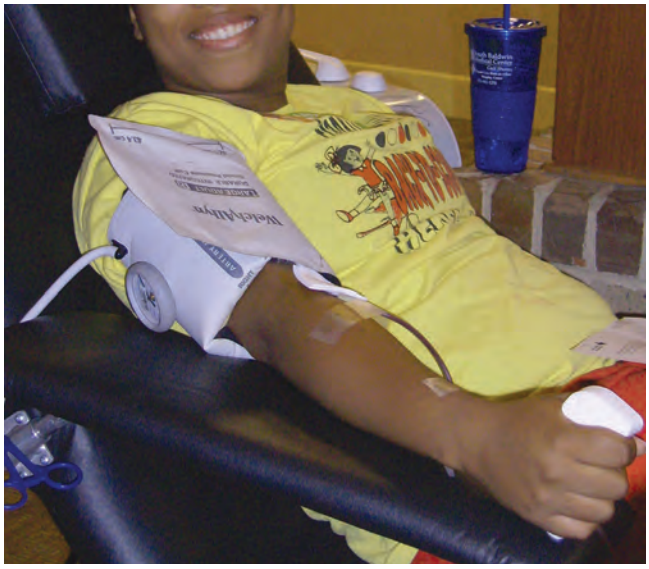
The conference registration fee covers conference syllabi, continental breakfast, lunch on Friday, and continuing education credits.

Reservations can be made by calling the USA Sickle Cell Center Administrative Office at (251) 470-5893 or online at www.usa-cme.com

Register early to enter for a chance to win free conference attendance at the 2013 Annual Sickle Cell Conference. Early registration deadline is August 10, 2012.

Something to Talk About.....

September 24, 2011 Blood Drive Follow-up:



Alpha Phi Alpha Fraternity, Inc, the *USA Comprehensive Sickle Cell Center*, the Sickle Cell Disease Association of America, Mobile Chapter and Franklin Primary Health Center held their 13th Annual Blood Drive on September 24, 2011. ***A record-breaking seventy-one potential blood donors*** gave their valuable time in support of this annual event. The goal of the drive was to collect 50 units of blood. Forty-seven units of blood were collected. Each unit obtained was separated into red cells and plasma possibly touching the lives of ninety-four patients, their families, and friends. Many thanks to the **Pacesetters Motorcycle Club who set the standard with the highest group participation for blood donors for the third consecutive year**. Other supporters of the blood drive were the Classic Corvette Club and USA Student National Medical Association. The sponsors express their sincere gratitude to those who came out in support of the blood drive. Remember, the lives you save may be yours, your family, friends, or neighbors. We are looking forward to an even larger turnout next year and hope to see you and your organization at the 2012 blood drive.

The 2012 Blood Drive is tentatively scheduled for Saturday, September 22, 2012 at Franklin Primary Health Center Medical Mall located on Dr. Martin Luther King Drive, Mobile, Alabama.

Submitted by: Ardie Pack-Mabien, CRNP

Healthy Choices and Lifestyles
Can Result In Living A Better Quality Of Life With Sickle Cell Disease

Sickle cell disease (SCD) is an inherited blood disorder diagnosed shortly after birth. In order for a person to have sickle cell disease, both parents must be carriers of the sickle cell gene, called sickle cell trait. The most common reason individuals seek medical attention with SCD is recurrent and/or chronic episodes of bone pain involving the arms, legs, and lower back. Blockage of blood flow by sickled red blood cells can affect any body organ causing end organ damage resulting in conditions such as stroke, chronic lung disease, kidney failure, avascular necrosis, and chronic leg ulcers.

Prior to the implementation of mandatory newborn screening, high infant mortality in SCD was more common in the first 5 years of life. Infants died from pneumococcal sepsis, meningitis, acute chest syndrome, and splenic sequestration crisis, most commonly. Individuals with SCD are now living longer and the quality of life has improved as a result of early diagnosis, parental education, improved access to medical care, better tools for risk assessment of stroke in children, and preventative medical strategies such as penicillin prophylaxis, pneumococcal vaccinations, Hydroxyurea, and more appropriate use of red blood cell transfusions.

More than 90 % of individuals with SCD will survive past age 20 (NIH 2002) with a median life expectancy in the forties for sickle cell anemia and the sixties for sickle-C disease.

Disease preventive strategies in SCD include the following diagnostic and laboratory tests: stroke risk assessment with transcranial doppler (TCD) for pediatric patients ages 2-16 years, chronic transfusion therapy for the child identified to be at risk for stroke, annual ophthalmology exam to evaluate for sickle retinopathy, routine dental cleaning, immunizations, gynecological evaluation, and prostate evaluation. Disease prevention also includes eating a well-balanced diet, proper hydration, low impact exercise, proper hygiene, and relaxation activities. Individuals with SCD should consult with their physician before taking vitamin or herbal supplements such as iron and vitamin C. Ongoing patient and family education is an important component of the preventive medicine strategies allowing the individual with SCD to have a broader scope of knowledge regarding their disease. This allows the patient to participate in his or her care with a certain level of understanding and hopefully increased compliance with the recommended medical regimen.

Helpful hints to prevent or reduce the severity of long term complications of sickle cell disease:

- Any child with SCD who has a temperature of >101.4 and other signs of infection such as, chills, lethargy, irritability, or poor feeding habits should be seen by a physician immediately.
- Have regular physical examination every 3-6 months as directed by your physician/healthcare provider.
- Take medications as directed and comply with diagnostics studies as recommended by your physician/healthcare provider.
- Have ophthalmology exam done annually, starting at age 6 years.
- Complete regular immunizations against common infections. The following are important vaccinations for everyone with sickle cell disease: pneumococcal, haemophilus influenza, influenza, meningococcal, and hepatitis B vaccines.
- Get sufficient rest; eat a balanced diet; and drink at least six 8oz glasses of water daily.
- Dress appropriately according to the weather.
- Avoid smoking and second-hand smoke.
- Avoid excessive use of alcohol.
- Avoid physical overexertion and stress.
- Report the following to your physician: fever, cough, difficulty breathing, rapidly enlarging spleen, pain unresponsive to home pain medications, or new onset speech difficulty or weakness involving the arms or legs.

Submitted by: Ardie Pack-Mabien, CRNP

Attention Graduating seniors:

Scholarship information can be accessed at the following websites:

http://www.blackcollegedollars.org
http://www.fastweb.com
http://www.scholarships.com
http://www.schoolssoup.com

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Dr. Cecil L. Parker, Jr. Distinguished Endowed Lectureship: Securing the Future of Sickle Cell Education

The Dr. Cecil L. Parker, Jr. Distinguished Endowed Lectureship was implemented in April of 2008. This endowment was established to support sickle cell disease education for patients, physicians, nurses and allied health professionals in this community in perpetuity. It is the philosophy of the University of South Alabama Comprehensive Sickle Cell Center that an educated healthcare community will facilitate better healthcare delivery, improve consumer outcomes, prolong lives, and decrease healthcare disparities.

2012 heralds the 12th year the Sickle Cell Center will sponsor its regional conference. This conference is designed to bring state-of-the-art lectures on clinical and psychosocial issues impacting individuals with sickle cell disease. The distinguished lecturer for this year's conference is Dr. Robert J. Adams, Professor of Neuroscience and Co-Director of the Comprehensive Stroke and Cerebrovascular Program at the Medical University of South Carolina. He will speak on, "Primary stroke prevention works: the falling rate of childhood strokes in sickle cell disease". For the 2012 conference, the Center has partnered with the Sickle Cell Disease Association of America, Mobile Chapter. This partnership has allowed us to cast a broader net capturing psychosocial issues affecting consumers with sickle cell disease.

In the March 2011 newsletter, the endowment donations totaled $58,965. Our initial goal was to secure the first $100,000 by April 2012. The endowment must meet the $100,000 mark before earned interest can be used to support the Center's education agenda. Unfortunately, we did not make it but we are close. The current endowment total is **$95,031**. As Center Director, I applaud all of those who have given and continue to give to the endowment in support of sickle cell education. This has been accomplished through the grass root efforts of 147 individual donors and 12 corporate entities. If you have not made your donation, please do. If you have donated, please continue to give. As a community, let's surpass the initial goal of $100,000 by the end of December 2012. "We have only just begun".

Thank you for your support!

Please join faculty, staff, alumni and friends to honor Dr. Parker by making a gift today to the **Dr. Cecil L. Parker, Jr. Distinguished Endowed Lectureship**. All contributions are tax deductible.

For more information, please contact Racheal Banks at rbanks@usouthal.edu

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Visit the Comprehensive Sickle Cell Center website at:
http://www.usahealthsystem.com/sicklecellcenter