

Sickle Cell Today

USA Comprehensive Sickle Cell Center

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A Community in Action: Classic Corvette Club of Mobile



Left to Right: Steve Chumney, president and Delton Dubose, vice-president, Classic Corvette Club of Mobile.

True to its mission of “providing social interaction between members, their families and the community,” the Classic Corvette Club of Mobile has been a supporter of the University of South Alabama Sickle Cell Center and the sickle cell community for over 10 years. In September of every year, National Sickle Cell Awareness Month, this organization has adorned the annual blood drive held

at the Franklin Primary Health Center Medical Mall of Mobile, Alabama, with its’ beautiful corvettes. And, its’ members donate their blood and funds in an effort to provide the “gift of life” and support the educational agenda of the Sickle Cell Center. The University of South Alabama Sickle Cell Center and sickle cell community thank the Classic Corvette Club of Mobile for its service and support.

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

Community Blood Drive an Annual Event for Sickle Cell

The annual blood drive sponsored by Alpha Phi Alpha Fraternity, Inc., the USA Comprehensive Sickle Cell Center, the Sickle Disease Association of America, Mobile Chapter, and Franklin Primary Health Center was held on September 9, 2017 at the Franklin Memorial Complex Mall located at 1303 Martin Luther King Avenue, Mobile Alabama. 2017 marked the 19th year of this partnership where the blood drive is conducted annually during the month of *September* which is *National Sickle Cell Awareness Month*.

The success of the drive stems from participation by the Mobile community. Supporters of the blood drive are the: Classic Corvette Club, Student National Medical Association, USA Leadership Scholarship Program, Alpha Elites, Edith Mitchell Health Initiatives, and donors from across the Mobile community. While the goal of this drive was 50 units of blood, 35 units were collected.

The sponsors express their sincere gratitude to the community, local organizations and volunteers who came out in support of the blood drive. **Thank you for giving the “Gift of Life” through blood donation.** We are looking forward to a more successful blood drive in 2018 and hope to see you and your organization present.

The 2018 Blood Drive is tentatively scheduled for Saturday, September 8, 2018 at Franklin Primary Health Center Medical Mall located on Martin Luther King Drive, Mobile, Alabama.



Annual Sickle Cell Conference 2018

Sickle Cell Disease Practical Issues XVI: Pain: Pilot or Passenger ?

On Saturday, April 14, 2018 the USA Comprehensive Sickle Cell Center will host its 16th Annual Regional Sickle Cell Conference. National and local experts will present up-to-date information on treating patients with sickle cell disease.

A central theme of this year's conference will be pain management - indications and therapeutic targets.

To Register for the conference or for additional information visit : <http://www.usahealthsystem.com/newspecial-event>, email mchancel@health.southalabama.edu or call (251) 470-5893. Register online: <http://www.usa-cme.com>



Improving Healthcare Provider – Patient Communication

Jessica L. King, CRNP
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As a healthcare provider have you wondered why it seems more difficult to communicate with some patients versus others and what the reason might be? There are many factors that can contribute to ineffective communication. Like it or not factors such as social, cultural, geographical, educational, religious, gender, and generational factors can impact healthcare provider to patient communication.

The patient based approach addresses cross cultural core issues that we as providers should assess with each individual patient, such as: 1.) style of communication, 2.) mistrust, 3.) family dynamics and decision making, 4.) spirituality, and 5.) gender. A patient based approach allows the healthcare provider to learn from each patient and individualize care based on social and cultural factors that influence health beliefs, behaviors, and offers strategies to negotiate for better health outcomes.

Listed below are some tips to help assist healthcare providers:

- 1.) Be aware of your communication style and sensitive to preferences of your patient.
- 2.) Ask open ended questions to assess each patients understanding of their illness and treatment plan.

3.) When possible speak in lay terms and avoid medical terminology as much as possible.

4.) If you sense that your patient has any trust issues with health care you should address this openly to make an effort to build trust and provide reassurances of your intentions to help.

5.) Assess religious beliefs and concerns to determine whether or not the patient’s healthcare will be affected by certain tests and/or procedures such as a blood transfusion.

6.) Be open and aware of the different ways patients and their families view gender and family roles and attempt to accommodate when feasible.

7.) Remember the golden rule, “Do unto others as you would have them do unto you.”

Effective communication between the healthcare provider and patient is essential to promoting better outcomes.

Betancourt JR, Green AR, & Carrillo JE (2016, May 17). Cross-cultural care and communication.



Scholarships

Pediatric To Adult Care Transition (PACT)

T'Shemika Perryman, RN, PACT Coordinator
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The mission of the PACT program is to improve health and literacy through educational programs and a comprehensive, patient-centered health care delivery system. This system emphasizes self-management, patient-physician collaboration, and interdisciplinary care coordination directed at increasing patient education.

With the advances in health care, sickle cell patients are now living much longer and lead more productive lives. This gives them more opportunities for furthering their education, getting married, starting families and so much more. The PACT program offers opportunities for ACT/SAT prep, a learning resource and development center (LRDC) with laptops and internet access where the participants may come and apply for college, financial aid, and vocational rehabilitation. The program will now offer a Watson-Henderson scholarship. This scholarship was

established in December 2017 with a starting donation of \$500. The first recipients of this scholarship are slated for 2022. The scholarship is open to all PACT participants entering high school beginning in 2018. The eligibility requirements for this scholarship are: a minimum grade point average of 2.5, attendance to 2 of the annual open house events held at the LRDC, attendance to 2 of the educational/life enhancement classes, and an essay. This scholarship will hopefully motivate our participants to think and look beyond their sickle cell status and know that they can do and are expected to at least consider college as an option to life after graduation and continue on a positive track as part of transitioning from pediatric to adulthood.

From the Director's Desk

Physicians Attitudes and Practices in Sickle Cell Disease Pain Management

By Johnson Haynes, Jr., M.D., Director
University of South Alabama
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Pain is the most common reason individuals with sickle cell disease seek medical attention. Sickle cell pain episodes often require the use of strong pain medications, called opioids. Frequent use of opioids can lead to physical dependency in many and addiction in some. When taking opioid analgesics on a daily basis, physical dependency can be seen as early as 5 to 7 days. When opioids are required for pain relief for >5-7 days, the dose should be tapered in order to avoid physiologic symptoms (i.e. nasal congestion, diarrhea, nausea, vomiting, sweating and seizures) of withdrawal. Addiction

is not a physical dependence but, rather, a psychological dependence. Individuals who are addicted to opioids seek opioids for reasons other than control of pain. The use of opioids for acute pain is not addiction, regardless of the dose or length of time opioids are taken. Many physicians believe that patients with sickle cell disease are more likely to become addicted to pain medication than are other patient populations. **This is not true.** Addiction has been reported to occur in 0.2% - 2% of individuals with sickle cell disease. This does not differ from the rate of addiction seen in the general population.

In the December, 2005 issue of the *Journal of Palliative Care* Drs. Elise Labbe, Donald Herbert, and Johnson Haynes Jr. at the University of South Alabama published the results of a survey that assessed physicians' attitude and practices in the management of sickle cell pain episodes. This survey was sent to 286 physicians at seven National Institutes of Health-funded university-based comprehensive sickle cell centers. The survey assessed demographic information; and physicians' attitudes toward and knowledge of pain, pain treatment and drug addiction and abuse. Physicians reported varied pain management strategies, however, many believe that attitudes toward addiction and to patients in pain crisis may result in under treatment of pain. In rank order, barriers identified to providing optimal management of sickle cell pain episodes by physicians are listed below.

The results of this survey indicate that physicians might benefit from additional education regarding sickle cell disease, addiction to pain medication, how these drugs work, and the assessment and treatment of pain. Establishing an open, honest and trusting relationship with your physician is key to effective management of sickle pain episodes. The lack of establishing such a relationship results commonly in frustrated healthcare practitioners and patients. *Previously published in Sickle Cell Today, March 2006 Issue.*

RANK ORDER OF RESPONDENTS' BARRIERS TO OPTIMAL MANAGEMENT OF SICKLE CELL PAIN EPISODES

1. Lack of psychological support from patient's family and medical profession
2. Fear that patient is a drug abuser
3. Reluctance to prescribe opioids
4. Disbelief in patient's report of pain severity
5. Inadequate patient-reported pain assessment tools
6. Adversarial relationship between patient and healthcare provider
7. Lack of access to health care provider
8. Nurse reluctance to administer opioids
9. Differences in age, gender, race, and socioeconomic status between patient and provider
10. Range of analgesics available from institution's formulary and FDA-approved drug list
11. Concern over loss of medical license
12. State regulation of analgesics
13. Patient reluctance to report pain
14. Patient reluctance to take opioids
15. Most sickle cell patients are drug addicted

In the United States, it is estimated that:

- ✓ SCD affects approximately 100,000 people
- ✓ SCD occurs in about 1 in every 365 African-American births
- ✓ SCD occurs in about 1 in every 16,300 Hispanic-American births
- ✓ About 1 in 13 African-American babies is born with sickle cell trait (SCT)

Source: Centers for Disease Control and Prevention: World Health Organization; Piel et al. 2013, Lancet 381:142-51

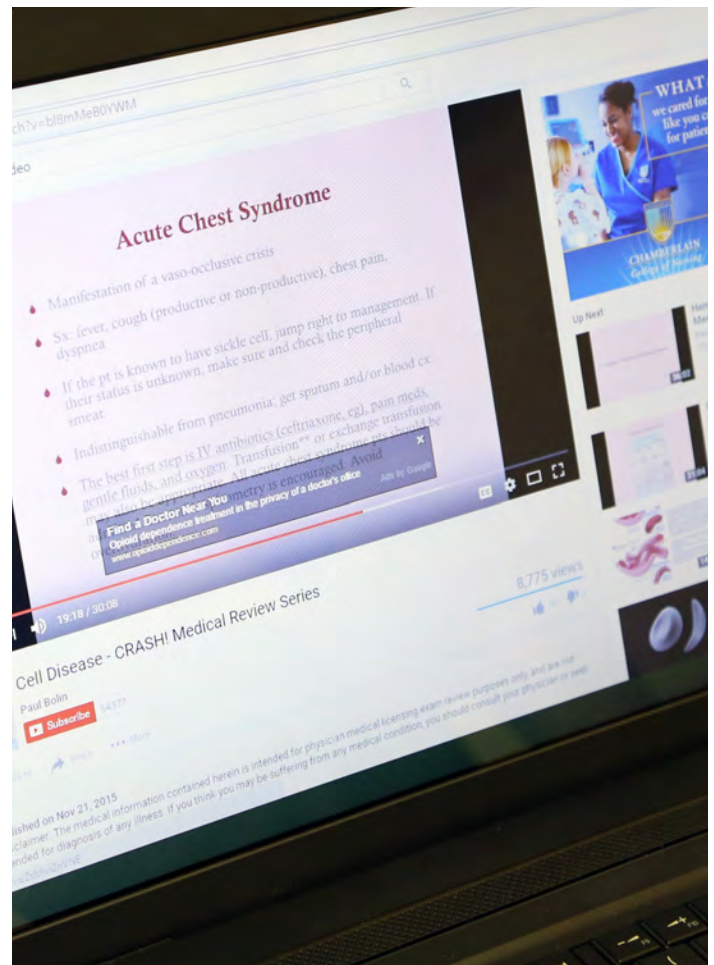
Globally, it is estimated that:

- ✓ SCD occurs in approximately 300,000 births annually
- ✓ SCD is most prevalent in malaria endemic parts of the world, primarily Africa, the Middle East, and South Asia
- ✓ In many African countries, 10% to 40% of the population carries the sickle-cell gene, resulting in estimated SCD prevalence of at least 2%

Source: Centers for Disease Control and Prevention: World Health Organization; Piel et al. 2013, Lancet 381:142-51

Current State

- ✓ More than 75 percent of adults with SCD with frequent pain crises fail to get hydroxyurea, which is the recommended treatment. Stettler N, McKiernan CM, Melin CQ, Adejoro OO and Walczak NB, "Proportion of Adults with Sickle Cell Anemia and Pain Crises Receiving Hydroxyurea," *Journal of the American Medical Association* 313, no. 16 (April 2015): 1671-72.
- ✓ Despite universal newborn screening for SCD in the United States, long-term follow-up after diagnosis was not performed in nearly one-third (30.8%) of cases. Kanter J and Kruse-Jarres J, "Management of Sickle Cell Disease From Childhood Through Adulthood," *Blood reviews* 27, no. 6 (November 2013):279-287.
- ✓ SCD is associated with high treatment costs. For an average person with SCD reaching age 45, total lifetime health care costs were estimated to be nearly \$1 million, with annual costs ranging from over \$10,000 for children to over \$30,000 for adults. Kauf TL, Coates TD, Huazhi L, Mody-Patel N and Hartzema AG, "The Cost Of Health Care For Children And Adults With Sickle Cell Disease," *American Journal of Hematology* 84, no.6 (March 2009):323-327.





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