

Sickle Cell Today

USA Comprehensive Sickle Cell Center

Volume 14 Issue 2

September 2017

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From the Directors Desk:

Will the War on Opioids Help or Hurt Sickle Cell Disease Patients? An Opinion Piece

Johnson Haynes, Jr., MD,
Director University of South Alabama Sickle Cell Center

In sickle cell disease (SCD), pain is the most common reason for hospitalization and office visits. While there are now two drugs, hydroxyurea and L-glutamine that are effective in pain prevention, opioid analgesics are the only medications, to date, shown to be effective in the treatment of pain crisis. To relieve pain and suffering is a responsibility of the physician and should not be taken lightly. As physicians we must remember the goal of therapy is to relieve pain, not to completely alleviate it. To effectively manage pain, trust between healthcare providers and patients is essential and the use of strong painkillers such as oxycodone, hydrocodone, hydromorphone, morphine and fentanyl are still needed to manage pain crisis in SCD.

Unfortunately, the potency and availability of these drugs, despite their high risk of addiction and overdose, have made them popular both as formal medical treatments and as recreational drugs. In 2015 the U.S. Drug Enforcement Administration reported that deaths due to overdose, particularly from prescription drugs and heroin, have reached epidemic proportions. At the 2017 Annual Meeting for the

Society of Hospital Medicine, Shoshana Herzig, MD, of Harvard Medical School reported that the traditional diagnostic and prescribing practices of hospitalists have inadvertently contributed to the increase in opioid overuse and overdoses. In the 2016 guideline for opioid prescribing from the Centers for Disease Control and Prevention, Charles Argoff, MD, director of the Comprehensive Pain Center at Albany Medical Center in Albany, New York, published that long-term opioid use often begins with treatment of acute pain and that more than 7 days of treatment is rarely needed. These two reported observations strongly support the coordination of care between hospitalists and outpatient physicians when managing pain is essential. The lack of care coordination (personal observation) is also potentially playing a role in the opioid crisis. Physicians should remember that if more than 7 days of an opioid is needed to control pain, close follow up and titration off the opioid is prudent to circumvent opioid withdrawal. As healthcare providers, we should also remember that pseudo-addiction (often misdiagnosed as addiction) can result when pain is under-treated.

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



In SCD pain can have many faces, acute, intermittent, chronic, and often varying in intensity. As healthcare providers we must listen to our patients and tailor pain management according to the clinical presentation. We must remember that guidelines are just guides to care, not standards of care. Equally important is we must escape our own biases when managing the subjective symptom of pain.

For the general population, the rapid increase in use and abuse of prescription opioids and non-prescription opioids in the U.S.

has led to the development of new Centers for Disease Control and Prevention guidelines for prescribing opioids. Locally, the Alabama Board of Medical Examiners, Medical Licensure Commission recently published risk and abuse mitigation strategies for prescribing opioids. The goal of these agencies is to promote medically appropriate utilization of opioids and to reduce opioid-associated morbidities and mortalities. In SCD it remains unclear what traditional prescribing practices used in the management of sickle cell-related pain plays in

the current opioid crisis. It does appear that a very ethnically, diverse, population, far beyond those affected with SCD, are impacted. Fortunately in America, every person, independent of race, color or creed is presumed innocent until proven guilty. This being said, individualized, disease-specific care is what remains most appropriate.

<https://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm>

<http://www.albme.org/Documents/Newsletters/2017V32No1.pdf>

20th Annual Blood Drive

Jessica L. King, CRNP
University of South Alabama
Comprehensive Sickle Cell Center

The members of Alpha Phi Alpha Fraternity, Inc., Beta Omicron Lambda Chapter; University of South Alabama Comprehensive Sickle Cell Center, Sickle Cell Disease Association of America, Mobile Chapter and Franklin Primary Health Center, will be sponsoring its' annual blood drive scheduled for Saturday, September 9, 2017 at Franklin Primary Health Center located at 1303 Martin Luther King Drive, Mobile, Alabama from 10am - 2pm. Blood donations collected will be used to meet the local demands of this community and surrounding areas. We greatly need you, your family, friends, and

coworkers to come out and support this worthy cause and meet this year's goal of 50 units. There will be drawings for door prizes and a light snack and a T-shirt will be provided for those who donate blood. Please come and participate by giving the "Gift of Life" through your blood donation. If you cannot come during the blood drive, you can donate one week before or after the blood drive to the Donor Center located at 35 North Sage Street, Mobile, Alabama 36607 and give your donation on behalf of Alpha Phi Alpha Fraternity. For operating hours and additional information, please call (251)544-6110.

Pediatric to Adult Care Transition:

EmPowering and EnAbling ExCelleNce Together

T'Shemika Perryman, RN, P.A.C.T. Coordinator
University of South Alabama Comprehensive Sickle Cell Center

The t-shirt design contest held in September of 2016 was a success. Clients in the PACT program submitted their designs and the new, official t-shirts will now be debuted on September 11, 2017 from 3pm-5pm in the Learning, Resource and Development Center (LRDC). The LRDC is located at 2451 USA Medical Center Drive (formerly Fillingim Street), MCSB Room 1515, Mobile, Alabama 36617. The transition team decided to host an open house of the LRDC annually during September in celebration of National Sickle Cell Awareness Month. This event will allow our young clients as well as their

parents to meet the adult care providers, Dr. Johnson Haynes, Jr., and Jessica King, CRNP. During this celebration, clients and their families will have a chance to tour the adult sickle cell clinic held in the USA Physician Group, Mastin Professional Building. In keeping with PACT's

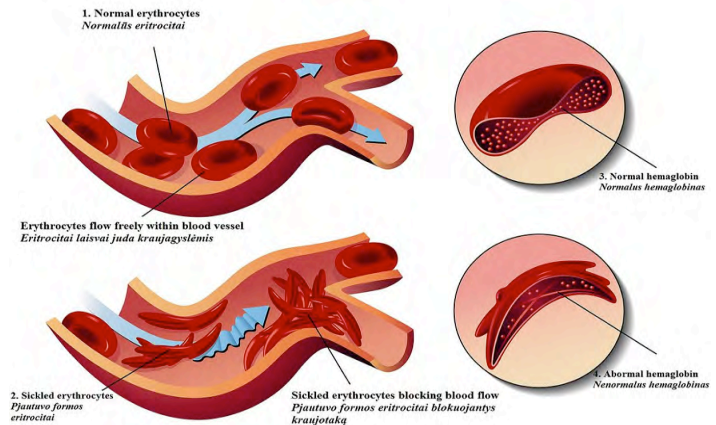


theme of Empowering, Enabling, Excellence, Together, these t-shirts represent the extraordinary talents and creativity of our participants. Way to go TEAM PACT!!! The PACT program's overarching goal is not only to

educate clients about their disease process but to also encourage them to be the BEST they can be!!! Hope to see you there for the unveiling of the phenomenal PACT t-shirt!!

FDA Approves a New Treatment for Children and Adults with Sickle Cell Disease

On July 7, 2017, the U. S. Food and Drug Administration (FDA) announced the approval of Endari for the treatment of sickle cell disease (SCD)-related complications (pain episodes and acute chest syndrome) in patients age 5 years and older. Endari is a powder form of the amino acid, L-glutamine, and exerts its effects by reducing "oxidative stress". It is taken twice daily, with food. In a Phase III clinical trial conducted at sickle cell centers throughout the United States (including the University of South Alabama Sickle Cell Center), two hundred - thirty individuals with SCD were randomized and placed on Endari (L-glutamine) or placebo (sugar pill). In this study, Endari caused a 25% reduction in the frequency of pain episodes, 33% reduction in hospitalization rates, fewer hospital visits due to pain episodes and a 60% lower occurrence of acute chest syndrome compared with patients who received the placebo. The most commonly reported side effects were nausea, abdominal cramps, headaches, cough, and pain in the chest, back, and extremities. However, less than 3% of the study participants discontinued the medication related to an adverse reaction (<http://www.drugdevelopment-technology.com/projects/>



[endari-for-the-treatment-of-sickle-cell-disease](http://www.drugdevelopment-technology.com/projects/endari-for-the-treatment-of-sickle-cell-disease)).

Details on the availability and prescribing of Endari have not been released by its maker, Emmaus Medical Inc. The approval of Endari as a new treatment in the management of SCD brings new hope to the more than 100,000 Americans affected with this potentially debilitating disease. For additional information on Endari as a therapy in the medical management of SCD, go to <https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm566084.htm>

Oh no, it's that time of the year again: Flu season is on its way!

Ardie Pack-Mabien, MSN, FNP-BC
University of South Alabama
Comprehensive Sickle Cell Center

The dreaded cold and flu season is but a sneeze away. Typically, the flu season begins between the months of October and May and usually peaks in the United States between December and February. According to the Centers for Disease Control and Prevention (CDC), thousands of Americans are infected with the influenza virus each year.

This virus is highly contagious and poses a serious risk for individuals living with sickle cell disease. To help prevent the spread of this virus, an annual influenza vaccination is recommended for all persons aged ≥ 6 months unless there are contraindications for the administration of this vaccine. This vaccination is particularly important

for individuals who are at an increased risk for severe complications from influenza, or at higher risk for influenza-related outpatient, emergency department, or hospital visits (<http://www.cdc.gov/flu/about/season/flu-season-2016-2017.htm>). Such individuals include children and adults with sickle cell disease who have diabetes, strokes, loss of spleen function and chronic conditions involving the lung (including asthma), heart (except isolated high blood pressure), kidney, and liver. See your healthcare provider to discuss the potential risks and benefits of this vaccine.

Health care providers usually begin offering the influenza vaccine soon after it becomes available and continues through the month of May or as long as the influenza virus circulates throughout the community. Of note, children ages 6 months through 8 years who are receiving the influenza vaccination for the first time should receive two doses of the vaccine at least four weeks apart (<http://www.cdc.gov/flu/about/season/flu-season-2016-2017.htm>). The vaccine is offered only as an injection (a shot) this flu season and can be obtained from your health care provider, health departments, clinics, urgent care centers, pharmacies, college health services, and employers. See your health care provider sooner rather than later to receive your vaccination as not to miss the benefits or possible shortage of this vaccine. Please keep this in mind as the availability and supply of vaccinations may be limited due to growing public demands.

No, the influenza vaccine does not cause an individual to develop the flu. However, there are some short-term and mild side effects of the influenza vaccine. That being said, exposure to an individual(s) with the influenza virus prior to receiving the vaccination may increase your risk of developing flu-like symptoms or the flu (<http://www.cdc.gov/flu/about/season/flu-season-2016-2017.htm>). Potential

side effects of the influenza vaccine include: soreness, redness, or swelling at the injection site, low grade fever, and generalized aches.

Individuals with the flu often miss days from work or school, pay costly copays for medical visits and medications, and may spread the virus to family members, coworkers, and the general public.

To help prevent the spread of the flu, the CDC recommends:

- Proper handwashing with soap and water or hand sanitizer,
- Turn your head and cough or sneeze into the sleeve of your elbow or napkin,
- Stay at home if you are sick with the flu,
- See your health care provider for your influenza vaccination, and
- Contact your health care provider for flu-like symptoms:
 - o Cough
 - o Sore Throat
 - o Runny Nose, Stuffiness or Congestion
 - o Fever
 - o Fatigue
 - o Headache or Body Aches
 - o Diarrhea and vomiting although more common in children

For additional information about the influenza virus, spread, prevention, and vaccine go to the Centers for Disease Control and Prevention website at: <http://www.cdc.gov/flu/protect/keyfacts.htm>



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.

Additionally, experts will address effective transitioning from pediatric to adult healthcare and the appropriate use of hydroxyurea in the young adult on chronic transfusions who were identified as having a high risk for stroke in childhood.

The conference targets physicians, physician assistants, nurse practitioners, nurses, pharmacists, and

allied health professionals. It is supported by the Dr. Cecil L. Parker, Jr., Lectureship Endowment, which was created to address the educational needs of the clients and health care providers of the Gulf Coast community.

The conference will be held from 8 a.m. to 4 p.m. (location to be determined). Register early for a chance to win complimentary admission to the Annual Regional Sickle Cell Conference 2018. The early bird registration deadline is Monday, March 26, 2018.

For additional conference information visit : www.usahealthsystem.com/sicklecellcenter, email mchancel@health.southalabama.edu or call (251) 470-5893.



The University of South Alabama College of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

Scholarly Activities

Improving the Transition Process for the Adolescent and Young Adult with Sickle Cell Disease

For more than 20 years, Ardie Pack-Mabien, MSN, FNP-BC has provided compassionate and comprehensive medical care and education for transitioning adolescents and young adults with sickle cell disease at the University of South Alabama Comprehensive Sickle Cell Center (the Center). These services are offered in the outpatient pediatric and adult sickle cell clinics. The pediatric clinics are held on Tuesday and Friday mornings from 8:30am to 11:00am at the Strada Patient Care Center. For young adults transitioning to adult services, this clinic is held on Thursdays from 8:30am to 12:00 noon at USA Physician Group, Mastin Professional Building.

Ms. Pack-Mabien is currently a Nursing, Doctoral of Philosophy (PhD) candidate at the University of Alabama at Birmingham. For her dissertation, she will examine the transition process employed in the Center, factors that may influence successful transition, and patient adaptation to the transfer of care to adult services. The Center offers transition preparation services through the Pediatric to Adult Care Transition (PACT) program. This program was implemented in 2012 to address the transition needs of this growing and vulnerable population.

While in pursuit of her doctoral studies on the transition process, Ms. Pack-Mabien recently received the Love for Learning Scholarship from Phi Kappa Phi Honor Society to support the research for her dissertation, "Participation in a Transition Program as an Essential Strategy for Successful Transition: A Mixed-Methods Research Study." The Love of Learning Scholarship is given annually to 200 active Phi Kappa Phi members

nationwide to fund post-baccalaureate professional development.

Lastly, Ms. Pack-Mabien will speak at the 11th Annual Advanced Nursing Practice Conference sponsored by the Nurse Practitioner Alliance of Alabama in Birmingham, Alabama, October 27-28, 2017. At this national conference, she will present an overview of the intersection of transition in the lives and medical management of the adolescent and young adult with SCD and preliminary findings of her dissertation.



The USA Comprehensive Sickle Cell Center is Proud to Announce Its 2017 Graduates

Congratulations to our high school grads: Carllisha Thomas- Baker High School, Kenya Tucker-Murphy High School, Erykah Austin- Chickasaw High School, Kelton Robinson-Chickasaw High School, Briana Evans-Pascagoula High School, Carrington Pugh-Murphy High School, Jadasia McCall- Baldwin County High School, MaKayla Lucky- Baker High School, Ruby Staten

Congratulations to our college grads: Chandler Dix- University of South Alabama, Daryl Henderson- University of South Alabama-Engineering.

**Jai N. Patel, PharmD, BCOP
Chief, Pharmacology Research
Department of Cancer Pharmacology
Phase I Clinical Trials
Cancer/Pharmacogenomics Research
Carolinas Medical Center-Transplant Division
Levine Cancer Institute I
Carolinas HealthCare System**

Presenting:

Thursday, September 28, 2017 at 8:00 AM Medicine Grand Rounds; USA Medical Center Conference Center; 2451 USA Medical Center Drive (formerly Fillingim St); 2nd Floor

“Pharmacogenomics of Opioids in the Treatment of Sickle Cell Pain Crisis”

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Sickle Cell Center Sponsored Summer Research Project

Rising sophomore medical student, Caleb Judge, presented the results of a summer research project titled, Role of Angiotensin Converting Enzyme Inhibitors/ Angiotensin Receptor Blockers for Protein-Wasting Nephropathy in Sickle Cell Disease at the 44th Summer Medical Students Research Day held on July 28, 2017 at the University of South Alabama College of Medicine. This work was supported by Errol Crook, MD; Ardie Pack-Mabien, CRNP and Johnson Haynes, Jr., MD. Congratulations Caleb for a job well done.

**Mary M. Hulihan, MPH, DPH
Health Scientist
NCBDDD/Division of Blood Disorders
Centers for Disease Control and Prevention (CDC)**

Presenting:

Thursday, October 12, 2017 at 8:00 AM Medicine Grand Rounds; USA Medical Center Conference Center; 2451 USA Medical Center Drive (formerly Fillingim St); 2nd Floor

“Sickle Cell Disease and the CDC Guidelines for Prescribing Opioids for Chronic Pain”

The University of South Alabama College of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

Thursday, October 12, 2017 at 4:00 PM Distinguished Scientist Lectureship Series; USA Medical Sciences Building, 5851 USA Drive North, 1st Floor Auditorium

“Health Disparity Reports: Should Sickle Cell Disease Be Included?”



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Gift Fulfillment:

- My check is enclosed (please make checks payable to USA - Parker Endowment Fund).
- Electronic Funds Transfer: (please send VOIDED CHECK with this form).
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Signature: _____ Date: _____

To contact the USA Office of Health Sciences Development, call (251) 460-7032.

This form and gift payments should be returned to: University of South Alabama - Office of Health Sciences Development
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