Sickle Cell Today

USA Comprehensive Sickle Cell Center

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TRISICKLE for Sickle Cel

TRISICKLE for Sickle Cell Campaign

As a result of mandatory newborn screening, penicillin prophylaxis, and pneumococcal vaccines, the life expectancy of babies born with sickle cell disease (SCD) in the United States has improved to the 4th and 5th decades of life. While survival with SCD has improved, one-third of adolescents and young adults delay or do not successfully transition to adult care and are lost to medical follow-up for the management of their SCD and its' complications. This improvement in survivorship from childhood to adulthood has resulted in the need to develop programs that foster successful transition and transfer of the adolescent and young adult with SCD to adult care.

To facilitate a more e ective transition process and transfer to adult sickle cell disease care, the **Pediatric to Adult Care Transition (PACT) Program**

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

TRISICKLE for Sickle Cell (continued)

was implemented at the University of South Alabama Comprehensive Sickle Cell Center on January 6, 2012.

The overall goal of the PACT program is to provide the adolescent and young adult ages 13-19 with a comprehensive patient-centered approach that emphasizes a better understanding of SCD and its' complications, appropriate use and misuse of medications, age-specific insurance benefits particularly with Alabama Medicaid, self-care, self-advocacy, patient-physician collaboration, and interdisciplinary care coordination between pediatric and the adult care providers. The motto of the PACT program is to "em**P**ower and en**A**ble ex**C**ellence **T**ogether" with the participants of this program and their family caregiver(s).

TRISICKLE for Sickle Cell Campaign:
What is it? This e ort was birthed by the Sickle Cell Center Development Council which is composed of community leaders, health care providers, clients, and family caregivers. It was developed with the purpose of promoting sickle cell disease awareness and to raise funds in support of programs and services o ered by the PACT program and USA Comprehensive Sickle Cell Center.

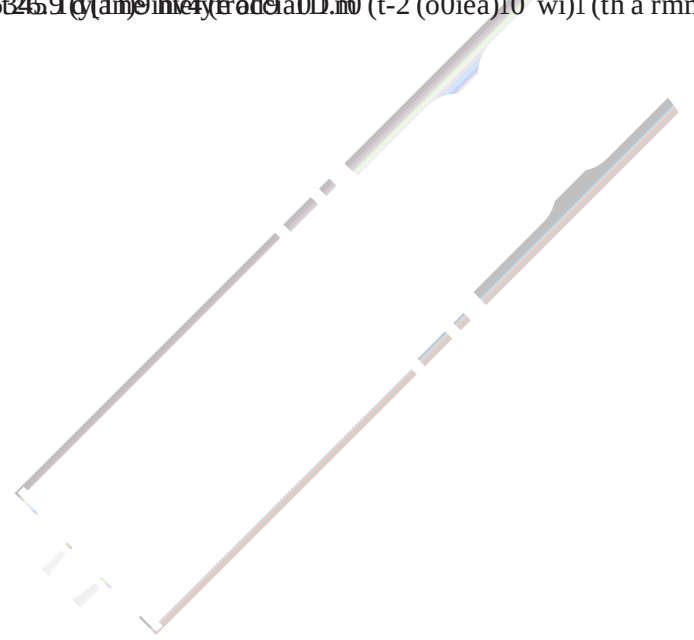
- In observance of "National Sickle Cell Awareness Month", the [illegible] had its' kick-o event at the Annual Sickle Cell Disease Blood drive held on Saturday, September 15, 2018. The campaign started o with great enthusiasm but clearly needs the support of the community.
- Take the pledge to TRISICKLE for Sickle Cell; see how far you can ride, and video yourself riding a tricycle.
- Don't forget to share your video on social media with the tag, #TriSickleForSickleCell and invite a friend to try!
- Pledge $1 per foot and help us raise awareness of and funds for Sickle Cell Disease.
- Donation link: visit facebook.com and search TRISICKLE for Sickle Cell Challenge.

For additional information the TRISICKLE for Sickle Cell Campaign and the PACT program, you can call the University of South Ak`a` l ` Cn l oqdgdmrhud Shbjkd Cdkk Cdmsdq `s 251 470-5893 nq 251 471-7703.

The Flu season will be here before we know it! Will you be ready?

The dreaded cold and flu season is but a sneeze, cough, and runny nose away. Typically, the flu season begins between the months of October and May and usually peaks in the United States between December and February. The flu season for 2017-2018 peaked during the early part of February with a record breaking hospitalization rate that exceeded prior years.

The influenza (flu) virus is highly contagious and poses a serious risk for individuals living with sickle cell disease. Individuals with the flu often miss days from work or school, pay cos2[3 koovf.1 (vs the U)1osMay anjdid (taliz)9s2 Td [m0 (t)2 ool, psp2 Td [Tals wa (hs of fr2talamico)9 (sm(en D



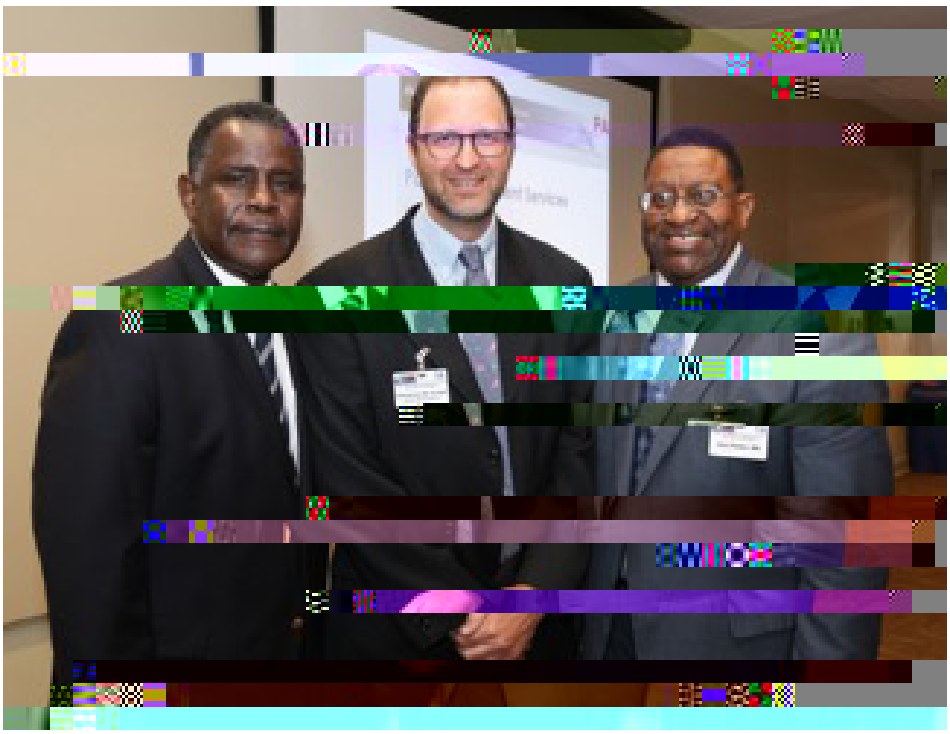
Sixty-three participants, consisting of physicians, PhD's, a Pharm D, physician assistants, nurse practitioners, registered and licensed practical nurses, social workers, and sta attended the 2018 conference. The 2018 conference, "Sickle Cell Disease Practical Issues XVI: Pain: Pilot or Passenger?," was the 16th conference conducted by the USA Sickle Cell Center. The conference theme is geared annually to address practical issues in medicine that impact the care of patients a ected with sickle cell disease (SCD). The 2018 conference focused on pain, as related to treatment, impact on sleep, and opioid prescribing regulations and requirements.

The Dr. Cecil L Parker, Jr., Sickle Cell Disease Distinguished Lecture was presented by David J. Axelrod, Associate Professor of Medicine and director of the adult sickle cell disease program at Thomas Je erson University Hospital-Thomas Je erson University in Philadelphia, Pennsylvania. He lectured on inpatient management of pain crisis in sickle cell disease. Other lecturers featured were local faculty members from University Hospital and Children and Women Hospital. William "Jet" Broughton, Professor of Medicine, Pulmonary/Critical Care Division, addressed sleep medicine with a focus on sickle cell disease and Hamayun Imran, Professor of Pediatric Medicine, Hematology/ Oncology Division, discussed the TWiTCH trial which found that high-risk children with sickle cell anemia and abnormal TCD velocities who have received at least 1 year of transfusions and have no MRA-defined severe vasculopathy, hydroxyurea treatment can substitute for chronic transfusions to maintain TCD velocities and help prevent primary stroke. Edwin Rogers, from the Alabama Board of Medical Examiners, provided insight on the new opioid prescribing regulations and requirements. This phase of the conference ended on the topic of patient controlled analgesia in the hospital management of pain which has become the preferred method of opioid administration in many hospitals across the country.

The last phase of the conference was sponsored by the American Society of Addiction Medicine (ASAM) on Risk Evaluation and Mitigation Strategies (REMS). This portion of the conference was free to all attendees and provided 2 AMA PRA Category 1 Credits. This course met the every 2 year, two AMA PRA Category 1 Credits requirements for Alabama Controlled Substances Certificate holders. With full participation in the conference, attendees were eligible to receive 7 AMA PRA Category 1 Credits.

The highlight of the 2018 conference was celebrating the retirement of Representative James Buskey after serving 42 years in the Alabama House of Representatives. Rep. Buskey was presented the Distinguished Service Award from the USA Comprehensive Sickle Cell Center.

Many thanks for the financial support from the USA Health System, Novartis Pharmaceuticals, Global Blood Therapeutics and ASAM. This support has been vital in keeping the cost of meeting registration a ordable and has enabled the USA Sickle Cell Center to provide a ordable continuing education for healthcare providers in the communities we serve.The next annual conference will be held in the spring of 2019.



Pictured left to right are: Drs. Johnson Haynes, Jr, David J. Axelrod, and Cecil L. Parker 6

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