

Sickle Cell Today

USA Comprehensive Sickle Cell Center

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Chi Eta Phi Sorority, Incorporated Gives Award to the Dr. Cecil L. Parker, Jr. Sickle Cell Disease Distinguished Lectureship Endowment

Chi Eta Phi Sorority, Inc. hosted its 62nd Boule' and Educational Conference in Mobile, Alabama, July 7- 11, 2013 at the Renaissance Riverview Plaza Hotel. Chi Eta Phi Sorority is a national nursing sorority. The theme of this years' Boule' was "Developing Healthy Communities through Advocacy,



Collaboration, Education, Leadership, Research and Service." The host city of each Boule' chooses a local organization to make a donation, and this year, the University of South Alabama Comprehensive Sickle Cell Center was the designee. This \$1000 gift goes to the Dr. Cecil L. Parker, Jr. Sickle Cell Disease Distinguished Lectureship Endowment. The proceeds from this endowment will be used to support the Annual Regional Sickle Cell Conference and educational needs of clients and providers serving the Gulf coast community. Many thanks from the University of South Alabama Comprehensive Sickle Cell Center to Chi Eta Phi Sorority for their leadership and generosity.

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

Supporting Quality Care

Five years ago, The Cecil L. Parker, Jr. Sickle Cell Disease Distinguished Endowed Lectureship was initiated in honor of Dr. Parker and his dedication to the care of patients with sickle cell disease and, at the same time, provide a permanent avenue to educate and equip health care providers to do the same. With the support of so many, the lectureship has and continues to have an enormous impact. Through their generous giving, members of the recognition societies have educated over 1,200 health care providers. This support has not only equipped health care providers with the knowledge and skills to deliver enhanced care, but most importantly has improved the lives of those affected by sickle cell disease.

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Parents have anxiety too...

Anxiety is an unpleasant state of inner turmoil, unpleasant feelings of dread, and the feeling of worry and uneasiness. Anxiety can be triggered by a multitude of situations occurring in life. Having a child with a chronic illness such as sickle cell disease, can be a source of anxiety particularly when transitioning from their pediatric provider of healthcare to their new adult doctor.

Parents invest heavily in the care of their children. Sickle cell disease multiplies that investment and results in building a tremendously strong bond between parents, the affected child and the pediatric healthcare provider. Children with sickle cell disease face the same challenges as their healthy counterparts along with the stress of managing their chronic illness. These challenges can be hard for parents as well.

For some parents, the transfer process from pediatric care to adult services entails a sense of loss of responsibility and control over their child's medical care. A goal of the Pediatric to Adult Care Transition program (PACT) is to address the concerns of parents as well as facilitate a seamless transfer of the child with sickle cell disease to adult services.

The time of transition should be viewed as a positive milestone not a dreaded event. Parents have a tremendous influence on their child. Listed below are tips for parents to decrease anxiety associated with the transfer process to adult care services.



- Get to know the pediatric medical management team as well as the PACT coordinator
- Ask questions and voice your concerns regarding your child's medical care
- Be involved in your child's medical management
- Keep an up-dated medical journal of all pertinent medical information such as the type of sickle cell disease your child has, hospital admissions, blood transfusions, immunizations and allergies
- Discuss school/vocational options with your case-manager prior to high school graduation
- Encourage responsibility and compliance while engaging your child in the transition process
- Remember the education process does not stop in the clinic for parent or child; empowerment through education must continue at home

We understand that during the transfer to adult services parents often need as much support as the transitioning client. We are here to help guide you and your child through the transition phase of the PACT program and promote them to adult services at age 19.

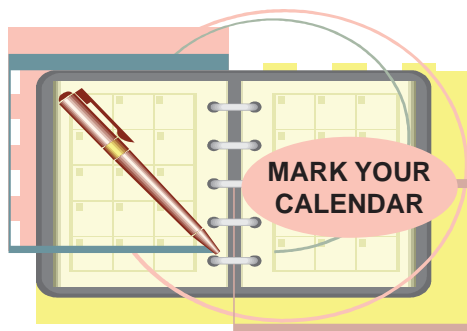
Brittany Brown, BSN, RN
PACT coordinator

"Never let the fear of striking out, keep you from playing the game."

Scholarly Activity

Articles Published

1. Ardie V. Pack-Mabien MSN, CRNP and Hamayun Imran, MD. Benefits of Delayed Fetal Hemoglobin (HbF) Switching in Sickle Cell Disease: A Case Report and Review of the Literature. *J Pediatr Hematol Oncol.* 2013; 00(00):1-3. www.jpho-online.com DOI: 10.1097/MPH.0b013e3182880dc8
2. Stefanos Intzes, MD, BSc, Ram V. Kalpathi, MD, Robert Short, PhD, and Hamayun Imran MD, MPH. Pulmonary Function Abnormalities and Asthma Are Prevalent in Children with Sickle Cell Disease and Are Associated With Acute Chest Syndrome. *Pediatr Hematol and Oncol.* 2013; ISSN: 0888-0018 print / 1521-0669 online; DOI: 10.3109/08880018.2012.756961
3. Ami Patel, Amra Zuzo, Hamayun Imran and Abdul Hafeez Siddiqui. Prevalence of Pneumococcal Bacteremia in Children with Sickle Cell Disease. *Pediatr Hematol and Oncol.* 2013; ISSN: 0888-0018 print / 1521-0669 online; DOI: 10.3109/08880018.2013.786157



THE 2014 USA ANNUAL SICKLE CELL CONFERENCE: Practical Issues XIII

The USA Comprehensive Sickle Cell Center is planning a dynamic and informative conference on "Pain in Sickle Cell Disease". The conference will be held Saturday, May 3, 2014. This conference will be addressing current and practical issues experienced by healthcare providers caring for those affected by sickle cell disease. The target audience is physicians, physician-assistants, nurse practitioners, nurses, and allied health professionals. This conference is supported by the Dr. Cecil L. Parker Jr. Sickle Cell Disease Lectureship Endowment.

POETRY Contest Winners!!



Congratulations to our poetry contest winners! A winner and 1st runner up were chosen from the submissions. Listed below is the winning poem submitted by Ms. Raven Evans. Raven is 16 years old and will be a senior at Murphy High School this year. Thanks to all the participants who entered the contest. We thoroughly enjoyed your submissions.

Young

Written by: Raven D. Evans

I am young.

I am hopscotch on the street and ice cream on a hot day,
I am tireless till one in the morning,
I am riding bikes through the park,
I am down the street, playing until the street lights come on,
I am young.

I am Nickelodeon and Cartoon Network,
I am on the phone for hours on end,
I am running through green pastures,
I am rolling down hills,
I am slumber parties,
I am enjoying life to its full potential,
I am young.

Raven will receive the first place prize of \$50.00 and our 1st runner up, Mr. Lynndrick Holmes will receive \$35.00.

The Last Visit

There was an energy in the air at school and in the neighborhood. The biggest basketball game of the season between South Gerard and Darden High was just a week away. All the guys were talking about "*Snowflake*". He was the baddest player these parts have seen since the Big "0". Guys were shooting "the ball" until they couldn't see the goal anymore and all you heard with each swish of the net was, "*Snowflake, Snowflake!*" That evening after school, some buddies and I stopped to shoot some hoops in the park. You see I usually don't do this a lot but I was so hyped about the big game I just had to show the boys I had "*game*," too. I got too hot and dehydrated and I knew it would happen. The *Stranger* came to visit that night as I cooled down. The *Stranger* is what I call the really bad pain that I get in my arms, my legs, and my back when I play too hard. I'm told my red blood cells block my blood vessels and when this happens the cells in my body suffocate and starve for food causing me to hurt. It's like the doors I keep so tightly closed, open. Sometimes no matter what I do, the *Stranger* forces his way into my body. My doctor gives me strong pain medicines to take and this usually is enough but this time, I couldn't bear it and my mom had to take me to the hospital.

Over the years, I have made many friends at the hospital. My best friend is old Doc Hayward. He has always been there over the years. I knew if I would just hold that door a little longer, Doc Hayward would take care of me and push the *Stranger* out of my life. As usual, when my mom and I arrived at the hospital, the nurses were ready to check my vitals, start my I.V. fluids, start the oxygen, and begin the I.V. pain medicine. Shortly thereafter, Doc Hayward checked in on me to make sure I was all right. I felt much better. I knew I had help. I was ready to fight the *Stranger* one more time and win.

After a few days, I improved and felt much better. Once again, the *Stranger* was shown he was not welcome and as he had imposed himself into my life, the door was closed in the *Strangers* face, told he was not welcome, and sent on his way. While effects of his visit lingered behind and little reminders of pain would occasionally knock at the door, the *Stranger's* over-bearing presence was no longer a

major factor and the rain, brutal thunder and sharp bolts of lightening lifted as the sun peeped through the last cloud. The I.V. was stopped and the oxygen flow ceased, and whatever little pain remained was easily managed and the rainbows of hope returned.

As I looked from my hospital window, things seemed so bright again. There was only one small dark cloud in the distance, which continued to hang low. Probably in the next day or two, I thought I would be discharged home. All I could think of was hanging out with my friends, Ryan and Jay and my little sister, Austin. As the day passed Doc Hayward came by for his daily rounds and told me I would be discharged home tomorrow if the x-ray of my arm was ok. I wasn't worried because the pain was all gone in my arm and the fever only lasted for two days. Later that day the attendant came to take me to x-ray. As we journeyed to the x-ray suite, he told me how *Snowflake* had scored forty-one points and grabbed sixteen rebounds in the big game. The best news was that my school, Darden High, had upset South Gerard even though *Snowflake* had the big game. I was sad I had missed the game, but glad I would be going home tomorrow. At this point the *Stranger* seemed so far away. The attendant left me in the reception area until they called me back for the xray. As I waited, a sudden darkness appeared in the nearby window. As I looked from the window the bright sun that had just peered through the window was no longer there. The little low hanging cloud had filled the sky. The rainbow was gone. Inside myself I knew. The *Stranger* was back knocking at my door, pushing to get in. I was not ready to fight again so soon. My energy was not yet restored from our recent battle, my armor not yet repaired. For the first time I had no warning. I had no time to prepare. It was too little, too late. This was the last fight, the last pain. I was never to fight or suffer again.

By Johnson Haynes, Jr, MD
July 15, 1996

The 2013-2014 Flu Season Is Rapidly Approaching

The Center for Disease Control and Prevention reported on Thursday, June 13, 2013 that at least 149 children died during last year's flu season. During the 2012-2013 flu season, H3N2, and Influenza B were the predominant flu strains identified. Adults age 65 and older accounted for more than half of all reported flu associated hospital admissions in the U.S. Health Day News reports. This was the highest number of recorded cases since the CDC started tracking flu-related adult hospital admissions in 2005-2006 (Health Day News June 2013).

What is influenza?

Influenza ("the flu") is a contagious respiratory illness caused by influenza viruses. It can cause mild to severe illness, and at times can lead to death. The Food and Drug Administration, World Health Organization, U. S. Centers for Disease Control and Prevention, and other institutions identify the influenza viruses most likely to cause illness during the upcoming flu season. The 2013-2014 flu vaccine will protect against three different flu viruses: H3N2 virus, influenza B virus, and the H1N1 virus. Young children, older adults, and people with certain health conditions such as sickle cell disease, lung disease and kidney disease are at high risk for serious flu complications such as pneumonia or acute chest syndrome. The best way to prevent the flu is by getting vaccinated each year.

What are the signs or symptoms of the flu?

The flu is different from a cold. The flu usually comes on suddenly. People who have the flu often feel some or all of these symptoms:

- fever or feeling feverish/chills
- cough
- sore throat
- runny or stuffy nose
- muscle or body aches
- headaches
- fatigue (tiredness)

Some people may have vomiting and diarrhea, though this is more common in children than adults.

What actions can I take to protect myself and my family against the flu this season?

Getting the flu vaccine as soon as possible after it becomes available each year is always a good idea. The protection you get from vaccination will last throughout the flu season. For information about vaccine supply this season, please visit <http://www.cdc.gov/flu/about/qa/vaxsupply.htm>.

In addition to obtaining your flu vaccine annually, you can take everyday preventive steps like staying away from sick people, washing your hands frequently to reduce the spread of germs, and cough or sneeze into your sleeve, elbow, or handkerchief, in a direction away from others. If you are sick with the flu, stay home from work or school to prevent spreading influenza to others, increase hydration, and contact your health care provider.

Who should receive the flu vaccine?

Adults and children who have a chronic disorder, requiring medical follow-up or hospitalization due to kidney disease, hemoglobinopathies (sickle cell disease), or conditions that compromise lung function should receive the flu vaccine annually. The flu vaccine promotes immunity to the influenza virus by stimulating specific antibody production.



When should I receive the flu vaccine?

The optimal time to receive the flu vaccine is October – November and prior to exposure to the influenza virus. The flu vaccine can be given through the month of December and later as long as the vaccine is available. The flu season may last as long as May. There have been shortages of the flu vaccine in the past and it is strongly recommended you do not delay obtaining your flu vaccine.

Don't delay contacting your sickle cell provider, primary care provider, or local health department for an appointment to get your flu vaccine while supplies are available.

Remember, "The early bird catches the worm and hopefully not the flu."

References: Health Day News June 2013. <http://www.cdc.gov/flu/about/qa/vaxsupply.htm>

Submitted by: Ardie Pack-Mabien, CRNP

THE SOCIAL WORKER'S CORNER

It's back to school for many of our sickle cell clients and as for the students classified as seniors, this year will perhaps present an entirely new set of decision-making challenges. There will be many students who will choose to explore educational options beyond the high school level. Some will decide to pursue a college degree while others may enroll in vocational training programs or community college. Developing a trade in the rapidly growing field of computer technology may be an option for many as well. Whatever the goals or aspirations, the importance of planning and preparation cannot be emphasized enough. For example, if pursuing a college degree is a post graduation goal, it is important to determine if your high school has an after school ACT or SAT Prep program. The school's guidance counselor may be able to provide students with information regarding accessing free ACT and SAT practice test booklets. Exam Prep websites can be extremely useful preparation tools as well. If further assistance is needed, contact your high school guidance counselor and/or the Sickle Cell Disease Association. The Sickle Cell Disease Association has certified teachers onsite to assist clients with college prep exams and with general graduation preparation. For more information on this or any of our other educational programs and services, please contact us at (251) 432-0301.

Until next time, so long from the Social Worker's Corner.

Adrienne Petite, LBSW
SCDAA

No One Knows What Lies Ahead, Every Three Seconds, Someone Needs Blood.

The USA Comprehensive Sickle Cell Center staff, Alpha Phi Alpha Fraternity, Inc., the Sickle Cell Disease Association of America, Mobile Chapter, and Franklin Primary Health Center 2013 Annual Blood drive is scheduled for Saturday, September 21, 2013. This partnership began in 2005 and is conducted during the month of September in recognition of the *National Sickle Cell Awareness Month*. The Blood drive will be held at the Franklin Memorial Complex Mall located at 1301 Martin Luther King Avenue, Mobile, Alabama.

The Blood drive has grown in participant numbers and lives affected each year. Sixty-four individuals presented as potential donors in the 2012 blood drive compared to fifty-three in 2011. The sponsors are extremely proud of the increasing number of first time donors; seventeen individuals presented as first time donors in 2012. Many lives in the community have been affected by this community based blood drive. One hundred forty-one lives were affected in 2012 by this precious gift of life through blood donations. The Comprehensive Sickle Cell Center extends sincere gratitude to the youth of this community, the Pacesetter Motorcycle Club, and other community organizations for their enormous support at the 2012 blood drive.

Thank you for your dedication and continued support and for giving the "Gift of Life" through blood donation. The life you save may be yours, your family, or friends. We hope to see you and your organization at the 2013 Blood Drive.



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