

Sickle Cell Today

USA Comprehensive Sickle Cell Center

Volume 8 Issue 1

March 2011

Table of Contents

Mobile Native Returns to Hometown to Lead Community Organization	1
From the Director's Desk	2
What's New in the USA Pediatric Sickle Cell Disease Community?	2
Annual Blood Drive Makes Goal: Teaming with the Community Works!!!	2
Make plans to attend the 2011 USA Annual Sickle Cell Conference	3
Dr. Cecil L. Parker, Jr. Distinguished Endowed Lectureship	3
In the Words of A Child My Sickle Cell Disease: Likes and Dislikes	4
USA Comprehensive Sickle Cell Center Main Office (251) 470-5893	
Fax (251) 470-5895	
Clinical Research (251) 471-7703	
Pediatric Clinic (251) 405-5147	
Adult Clinic (251) 470-5890	
Community-based Program (251) 432-0301	



Mobile Native Returns to Hometown to Lead Community Organization



Born and raised in Mobile, Nichelle Williams always knew that she would return to the State of Alabama and work to remove barriers that would improve the health and quality of life of those who need it most.

After spending two years in Washington, D.C., Williams recently returned home to become the new Executive Director of the Sickle Cell Disease Association of America, Mobile Chapter, Inc.

Williams has always had a passion for helping others. She is a 1998 graduate of Murphy High School, where she excelled in academics and cross-country. While at Murphy, Williams was heavily involved in community service, having served as a volunteer for a number of organizations, including the USA Women's and Children's Hospital, and even the Association she currently leads, volunteering as a tutor for children suffering from sickle cell disease in the Association's After School Tutorial program.

Following high school, Williams attended Spelman College in Atlanta, GA, where she continued her extracurricular involvement in campus life and the surrounding community. She co-founded the National Society of Collegiate Scholars (NSCS) on Spelman's campus, where she served as founding Vice President of Community Affairs. Williams received her Bachelor's in Political Science in 2002. Following her passion, she then went on to obtain her Master's at Emory University's Rollins School of Public Health, where she focused on health policy and management. There, she held several leadership roles with health related organizations, and worked with Children's Healthcare of Atlanta's Pediatric Partners of Decatur as a patient liaison to increase access to health care.

After graduate school, she took a year off to work with her dad and older brother at the law firm of Williams & Associates, before joining her younger brother at The University of Alabama School of Law. At UA Law, Williams was very active in the Student Bar Association, Black Law Students Association, and Farrah Law Society. She was also inducted into the Bench and Bar Legal Honor Society. Williams received her law degree in 2008, and soon after, she became a licensed attorney and member of the Alabama State Bar Association.

Williams continued her dreams of helping others in Montgomery, Alabama as a Health Care Fellow for the Alabama Appleseed Center for Law & Justice, where she worked on their Health Insurance Coverage Project and saw first-hand the inequalities and barriers she always pledged to address. Soon afterwards, Williams received an opportunity to work in Washington, D.C. on Capitol Hill for U.S. Representative Artur Davis (D-Ala.), where she remained for two years in a fast-paced environment, learning the federal legislative process and creating solutions to various issues facing the citizens of Alabama. What's more, in July 2010, Williams was selected as one of the 50 Most Beautiful people on Capitol Hill, coming in at Number 6.

After her tenure in D.C., Williams returned to lead the Sickle Cell Disease Association of America, Mobile Chapter, Inc. The Association serves nine counties in southwestern Alabama, and offers a comprehensive array of services aimed at increasing awareness of sickle cell disease and improving the quality of life for those suffering from the disease and their families. The Association provides confidential counseling services to individuals who test positive for sickle cell trait, and has a laboratory onsite to conduct testing for individuals interested in knowing their status. The Association also provides a number of supportive services for those with sickle cell disease, including an after school tutorial program for children in grades K-12, a summer enrichment program, case management services, pharmaceutical and medical assistance, and transportation.

Williams envisions leading the Association to a new beginning by improving on their services and making them more accessible to all individuals in the nine county area, increasing the visibility of the Association in the Mobile metro area, and expanding outreach services into the Hispanic community.

Williams has set high goals for the Sickle Cell Disease Association, and based upon her past record, we intend to watch as she accomplishes each of them.

FROM THE DIRECTOR'S DESK

Thanks to the Mobile Community

Johnson Haynes, Jr., M.D.
Director, USA Comprehensive Sickle Cell Center

As Director of the University of South Alabama (USA) Comprehensive Sickle Cell Center, I recognize the Center can be no better than the community in which it serves. The Center provides varying levels of services to over 500 clients affected by sickle cell disease. The primary faculty and staff consist of four physicians, nurse practitioner, registered nurse, and a secretary. The local community program, the Sickle Cell Disease Association, Mobile Chapter (SCDAA, MC), provides a social worker who assists with client services in the pediatric and adult sickle cell clinics. The Center assists the SCDAA, MC by providing lectures for their very unique Counselor/Educator Certification Program. Social workers, case managers, counselors and nurses from across the U.S. have benefited from training provided by this program. This relationship is longstanding and vital to the overall well-being and ability of the healthcare system and community program to deliver optimum services in promotion of good health and well-being for the mutual clients served. This issue of Sickle Cell Today contains

information meant to inform the community of the Center's recent past and current activities. As Center Director, I feel to whom much is given much is expected. The Center needs the continued support of this community and wants the community to know we are here to serve you.

In 2006, the USA Comprehensive Sickle Cell Center, for the first time, received donations generated from the University's Faculty Staff Annual Fund campaign. To all who gave, we would like to say thanks. **Please remember the next Faculty Staff Annual Fund campaign kicked off March 1, 2011 and the "USA Sickle Cell Center" must be listed as the designated recipient of your donation.** Your support will allow us to provide financial assistance to individuals without means to meet health care expenses and facilitate the implementation of educational programs related to sickle cell disease for the Mobile Community and surrounding areas.

The University of South Alabama Comprehensive Sickle Cell Center has been a part of the Mobile community for over 23 years and looks forward to serving this community for many years to come. From the Center to the community, the faculty and staff would like to say, thank you for all you have done and for the support you have given us.

Until next time, remember, **"Together we can move mountains"**.

What's New in the USA Pediatric Sickle Cell Disease Community?

The USA Comprehensive Sickle Cell Center's faculty and staff proudly welcome Dr. Abdul Hafeez Siddiqui to the pediatric team caring for children affected by sickle cell disease. Dr. Siddiqui, a pediatric hematologist/oncologist, is an Assistant Professor of Pediatrics in the College of Medicine. Dr. Siddiqui received his medical degree from Dow Medical College in Pakistan. He completed a residency in pediatrics from John H Stroger Hospital of Cook County, Chicago, IL and then proceeded for a three year fellowship in pediatric hematology/oncology at Children's Hospital of Michigan, Wayne State University, Detroit, MI. Dr. Siddiqui is board certified in pediatrics and has published and presented data regarding his clinical and basic science research at various national meetings. Dr. Siddiqui joins the pediatric hematology/oncology team that includes Drs. Hamayun Imran and Felicia Wilson, 2 nurse practitioners and 2 full time registered nurses.



According to Dr. Imran, the new Medical Director of the pediatric outpatient and inpatient hematology/oncology services and student and resident teaching liaison," as the division enlarges, the team is committed to expanding its educational activities, research activities and clinical endeavors which include increased participation in clinical trials available to children with sickle cell disease". Currently, the center is participating in a multicenter National Institutes of Health sponsored pediatric clinical trial called TCD with Transfusions Changing to Hydroxyurea (TWITCH). The University of South Alabama is one of twenty seven sites nationwide and was selected for participation due to its excellence and expertise in the field of sickle cell disease. This trial will be pivotal in understanding the benefits of hydroxyurea therapy and may provide an end point to the chronic transfusion therapy for children who are at a high risk of developing a future stroke. The trial will be open for enrollment in the immediate future. Families are encouraged to discuss eligibility for this trial at their next scheduled appointment.

Hamayun Imran, MD, MSc
Medical Director,
Division of Pediatric Hematology/Oncology

Annual Blood Drive Makes Goal: Teaming with the Community Works!!!

Each year, beginning in 2005, the USA Comprehensive Sickle Cell Center teams with Alpha Phi Alpha Fraternity, Inc, the Sickle Cell Disease Association of America, Mobile Chapter and Franklin Primary Health Center to sponsor a blood drive in September which is National Sickle Cell Disease Awareness Month. This year's blood drive was held on September 25, 2010 and was a huge success. The goal of the blood drive was to collect 49 units of blood. Fifty-three people presented as possible blood donors and 43 were actually able to give. Six donors gave what was equivalent to two units using the ALYX procedure which allowed us to reach the 2010 goal of 49 units. Each unit of blood obtained was separated into red cells and plasma possibly touching the lives of one hundred forty-seven individuals. For the second year, the Pacesetter Motorcycle Club set the standard with the highest group participation for blood donors. **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 2011 blood drive.

The 2011 Blood Drive is tentatively scheduled for Saturday, September 24, 2011 at Franklin Primary Health Center located at 1303 MLK Drive, Mobile, AL.

MAKE PLANS TO ATTEND THE 2011 USA ANNUAL SICKLE CELL CONFERENCE

The 2011 Sickle Cell Conference, Practical Issues XI: Cost Containment of Healthcare Delivery in the Era of Healthcare Reform is scheduled for April 9, 2011. The conference will be held from 8:00am until 3:30pm at the University of South Alabama, Student Center Ballroom. The Keynote speaker will be Dr. Jane S. Hankins from St. Jude Children's Research Hospital. She will speak on, "The Use of Hydroxyurea Therapy in Children with Sickle Cell Disease".

This year's conference will feature Karen F. Marlowe, PharmD, BCPS, CPE, Assistant Dean, Auburn University, Harrison School of Pharmacy as the luncheon speaker. Dr. Marlowe will speak on, "Opioids Risk, Evaluation and Mitigation Strategies: Potential to Change Us All".

Other speakers will be University of South Alabama faculty, Dr. Allen Perkins, (Healthcare Reform Update), Dr. Johnson Haynes, Jr, (Multi-organ Failure Syndrome in Sickle Cell Disease), Dr. Abdul Siddiqui (Transfusion Therapy in Sickle Cell Disease), and Dr. John A. Vande Waa (Management of Catheter-related Infections). All lectures will be 45 minute presentations with 15 minutes allotted for questions.

A continental breakfast and box lunch will be provided at the conference.

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 2012 Annual Sickle Cell Conference. **Early registration deadline is March 25, 2011.**

CEU's will be available for registered conference attendee.

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

The University of South Alabama designates this live activity for a maximum of 6 *AMA PRA Category 1 Credit(s)*[™]. Physicians should only claim credit commensurate with the extent of their participation in the activity.

"The project described was supported by Award Number P20MD002314 from the National Center on Minority Health and Health Disparities. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Center on Minority Health and Health Disparities or the National Institutes of Health."

Dr. Cecil L. Parker, Jr. Distinguished Endowed Lectureship

During the 8th Annual University of South Alabama Regional Sickle Cell Conference held in April of 2008, a special announcement was made that the keynote address for the conference would be named the **Dr. Cecil L. Parker, Jr. Distinguished Endowed Lectureship** and an endowment would be established to support sickle cell education for patients, physicians and allied health professionals in this community in perpetuity. The University of South Alabama chose to honor Dr. Parker not only for his service to USA but for his extensive and lengthy medical career of caring for adult patients affected with sickle cell disease. In 1986, Dr. Parker started his private practice in Mobile in Internal Medicine. Shortly thereafter, he was named the Director of the USA Adult Sickle Cell Center and served in this position for nine years. Even after resigning his post as Director, Dr. Parker continues to support the USA Comprehensive Sickle Cell Center.

The mission of the USA Comprehensive Sickle Cell Center is to improve the lives of persons affected by sickle cell disease through state-of-the-art clinical care, clinical research and education. The establishment of the endowment is a critical step in assuring the necessary educational outreach is and will always be in place to serve our patients and healthcare professionals. We believe a well informed healthcare community is essential and translates to optimum patient care and outcomes.

Since the establishment of the endowment in 2008, the current donations total **\$58,965**. This has been accomplished through the grass root community efforts of 125 individual donors and 6 corporate donors to date. Before any monies can be used to support the education agenda of the sickle cell center, a minimum of \$100,000 is required. From the Center's faculty and staff, we would like to say thanks for all the gifts made thus far into the **Dr. Cecil L. Parker, Jr. Distinguished Endowed Lectureship**. As you can see we have a ways to go to reach our goal. 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 before April 2012.



(L to R) Dr. Cecil L. Parker, Jr. ; Dr. Johnson Haynes, Jr.
Rufus Hudson, RBC Bank

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 Travis Grantham at tgrantham@usouthal.edu

Office of Medical Development, 650 Campus Drive, Suite 2150, Mobile, AL 36688
(251) 460-7032

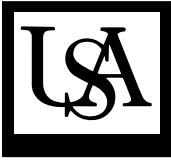
Attention Graduating Seniors: The 2011 "Kermit B. Nash Academic Scholarship" application is currently available online for your convenience at <http://www.sicklecelldisease.org/>. This scholarship is limited to individuals affected by sickle cell disease. Additional scholarship information can be accessed at the following websites:

<http://www.blackcollegedollars.org/>

<http://www.fastweb.com/>

<http://www.scholarships.com/>

<http://www.schoolssoup.com/>



University of South Alabama
Comprehensive Sickle Cell Center
2451 Fillingim Street, MCSB 1530
Mobile, AL 36617-2293

Non-Profit
U.S. Postage
PAID
Mobile, AL
Permit No. 506

TM



In the Words of A Child My Sickle Cell Disease: Likes and Dislikes

"Some days are difficult and on the other hands it can be smooth sailing. My sickle cell pain feels like someone has hit me with their fist. My body feels weak and restless. After all is said and done I feel like a rejuvenated person".

By Jaylon Smith, USA Pediatric Sickle Cell Clinic

Sickle cell disease (SCD) is one of many genetic disorders affecting children chronically in the United States. SCD is diagnosed during the newborn period as well as in older patients by hemoglobin electrophoresis, high performance liquid chromatography, or DNA analysis. Screening for SCD and trait was implemented in Alabama in 1988, universal newborn screening for SCD became mandatory August 2006 in all 50 states in the U.S. as well as the District of Columbia, Puerto Rico, the U.S. Virgin Islands, and Guam. In the U.S., an estimated 2,000 infants are diagnosed with SCD annually and over 30,000 students are affected with SCD.

The clinical severity of SCD is variable. Some individuals have very mild disease while others have severe disease and death at an early age. Children account for one fourth of the hospital admissions seen in individuals with SCD. Febrile illness/infection (29 percent), lung complications (27 percent) and disease prevention strategies requiring blood transfusions (21 percent) are the leading cause of hospitalizations in the school age child with SCD. This disease does not only affect the child's physical well-being but also affects their mental and spiritual well-being. A well informed community consisting of family, healthcare and psychosocial professionals, and concerned citizens are essential to the overall health and development of the child with SCD.

Submitted by: Ardie Pack-Mabien, CRNP

References:

Amendah, D., Mvundura, M., Kavanagh, P., Sprinz, P., & Grosse, S., (2010). Sickle cell disease-related pediatric medical expenditures in the U.S. *American Journal of Preventive Medicine*. 38(4), s550-556.

Day, S. and Chismark, E. (2006). The cognitive and academic impact of sickle cell disease. *The Journal of School Nursing*. 22(6), 330-335.

National Newborn Screening and Genetics Resource Center. (2006, August 15). National newborn screening status report update. Austin, Texas. Author

Steiner, C. and Miller, J. *Sickle Cell Disease Patients in U.S. Hospitals, 2004*. HCUP Statistical Brief #21. December 2006. Agency for Healthcare Research and Quality, Rockville, Md. <http://www.hcup-us.ahrq.gov/reports/statbriefs/sb21.pdf>

Wethers, D. (2000). Sickle cell disease in childhood. Part I, Laboratory diagnosis, pathophysiology, and health maintenance. *American Family Physician*. 62(5), 1013-1020, 1027-1028.