

Sickle Cell Today

USA Comprehensive Sickle Cell Center

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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

University of South Alabama Comprehensive Sickle Cell Center Development Council

Cheryl P. Franklin, DNS, RN - Chair, Sickle Cell Center Development Council

In October 2015, Dr. Johnson Haynes Jr. initiated the University of South Alabama Comprehensive Sickle Cell Center Development Council (SCC-DC). The express mission of the SCC-DC is to "assist the Comprehensive Sickle Cell Center (CSCC) Director in securing private gift support, creating awareness of programs and needs, and engaging members of the community with the CSCC through education and research." The first meeting was held in January 2016.

The Council is comprised of 12 members who will serve three-year terms. Members may serve two consecutive terms and are eligible for reappointment. Meetings are held quarterly. SCC-DC members bring a myriad of backgrounds, including marketing, communications, journalism, graphic design, nursing, engineering, medicine, accounting, law and clergy. Members also include individuals affected by sickle cell disease or trait and a parent of a child with sickle cell disease.

The SCC-DC will serve as an advocate for those affected by sickle cell disease and actively support the University's development staff in fundraising efforts and activities through the engagement of physicians and staff, community leaders, local healthcare facilities, and individuals

passionate about the care and treatment of individuals with sickle cell disease. While only in its infancy, the SCC-DC has hit the ground running. In celebration of World Sickle Cell Day, June 16, 2016, the SCC-DC and USACOM sponsored the first community-based, Meet and Greet celebration ever held in the 37-year existence of the CSCC. This event was hosted at the University of South Alabama Faculty Club.

The goal of the event was to introduce community leaders and organizations to the Council and its mission. Following this event, on June 21, 2016, Drs. Johnson Haynes, Jr. Director of the USA Comprehensive Sickle Cell Center, and Cheryl P. Franklin, Chair of the SCC-DC, were interviewed by Kelly Jones of WPMTV 15. The focus of the interview was sickle cell treatment and resources.

Future Council plans include engaging civic, social and educational organizations to raise awareness of sickle cell disease and its impact on patients, families of affected individuals, and the community. Inquiries may be directed to the USA Comprehensive Sickle Cell Center at (251) 470-5893.

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



MEET THE USA COMPREHENSIVE SICKLE CELL CENTER'S NEWEST ADDITION TO THEIR HEALTH CARE TEAM.



Jessica L. King, CRNP

The USA Comprehensive Sickle Cell Center healthcare team invites you to join them in welcoming their newest health care team member, Ms.

Jessica King, BSN, MSN, FNP, CRNP.

Ms. King graduated with her bachelor's degree in nursing from the University of South Alabama in 2003. While pursuing her master's degree Ms. King practiced as a registered nurse for the Infirmiry Health Care System, as a critical care nurse within the Intensive Care Unit, and Emergency Room. Ms. King graduated with her Master's degree in Nursing from the University of South Alabama in December, 2011. She received her Family Practice Nurse Practitioner Certification from the American Academy of Nurse Practitioners (AANP) in April, 2012. She is a member of the Sigma Theta Tau Honor Society, the AANP, and Bay Area Nurse Practitioner Association. Ms. King has come to the Sickle Cell Center after serving the Baldwin County community for the past four years as a

family nurse practitioner at an urgent care clinic located on the Eastern Shore where she provided primary health care for both pediatric and adult patients.

As a part of the USA Comprehensive Sickle Cell Center health care team, Ms. King will function as a nurse practitioner in a collaborative practice with Dr. Johnson Haynes Jr. and will work alongside Ardie Pack-Mabien BSN, MSN, FNP, CRNP. Ms. King will provide inpatient and outpatient care for adults with sickle cell disease. She will also assist the healthcare team in ongoing educational activities conducted in the Pediatric to Adult Care Transition Program (PACT) and will participate in ongoing clinical research and pharmaceutical-sponsored clinical trials. Ms. King may be reached at (251) 445-9159.

The 2016-2017 Flu Season will soon be here!

Ardie Pack-Mabien, CRNP

According to the Centers for Disease Control and Prevention (CDC), routine annual influenza vaccination is recommended for all persons with sickle cell disease aged ≥ 6 months who do not have contraindications.

The hot and humid days of summer will soon be over. The influenza season will be here before we know it which typically begins between October and May and usually peaks in the United States between December and February. Vaccination to prevent influenza 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.

Health care providers usually begin offering the influenza vaccine soon after it becomes available and if possible by October to ensure protection during the influenza season. Vaccines are generally available through the month of May or as long as the influenza virus is circulating throughout the community.

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 out on the benefits of this vaccine. Please keep in mind the availability and supply of vaccinations may be limited due to growing demands by the general public.



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 (<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. 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>).

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.

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

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 healthcare provider for your influenza vaccination, and
- Contact your healthcare provider for flu-like symptoms:
 - Cough
 - Sore Throat
 - Runny Nose, Stuffiness or Congestion
 - Fever
 - Fatigue
 - Headache or Body Aches
 - Diarrhea and vomiting although more common in children

18th Annual Blood Drive

Ardie Pack-Mabien, CRNP



The members of Alpha Phi Alpha Fraternity, Inc., Beta Omicron Lambda Chapter, University of South Alabama Comprehensive Sickle Cell Center, Franklin Primary Health Center Inc., and Sickle Cell Disease Association of America, Mobile Chapter will be sponsoring its' annual blood drive scheduled for Saturday, September 10, 2016 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 55 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 out during the blood drive, you can go one week before or after the blood drive to the Donor Center located at 3442 Demetropolis Road, Mobile, Alabama 36693 to give your donation on behalf of Alpha Phi Alpha Fraternity. For the hours of operation and additional information, please call 1-800-448-3543.

ZIKA Virus: Simple Facts and Precautions **Ardie Pack-Mabien, CRNP**

According to the Centers for Disease Control and Prevention, the Zika virus is contracted through the bite of an infected Aedes species mosquito found worldwide including the United States. This virus can be spread by an individual who has been infected with the virus through sexual contact, pregnant women to her unborn fetus, and although not confirmed and in rare cases, blood transfusions (Centers for Disease Control and Prevention; National Institute of Allergies and Infectious Disease). Most individuals infected with this virus will not have symptoms or become sick. However, some individuals infected with this virus will develop mild symptoms such as fever, rash, joint pain involving the hands and feet, or conjunctivitis (redness and swelling involving the eye), muscle pain, and headaches (Center for Disease Control and Prevention). Symptoms can last from several days to one week. In other cases, this virus can result in severe damage to the nervous system. In addition, an infected mother can pass the virus to her unborn fetus during the pregnancy or during the delivery. Effects of this virus on the unborn fetus can result in: (a) severe birth defects of the brain and eye; (b) hearing deficits; and (c) impairment in growth (Centers for Disease Control and Prevention).

Here are some recommendations by the Center of Disease Control and Prevention to prevent the spread of this virus:

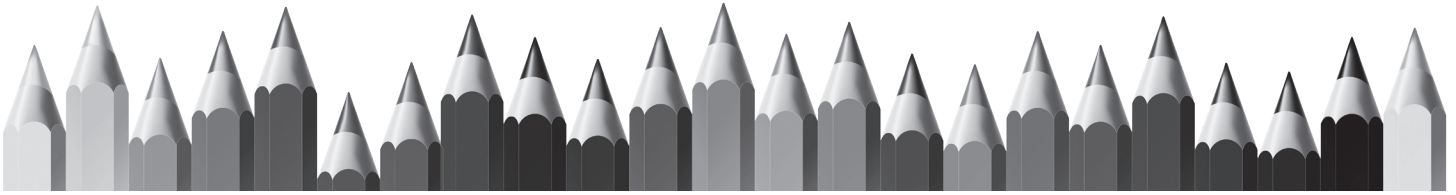
- Wearing long-sleeve shirts and long pants.

- Using mosquito repellent on the clothes of adults, children, and infants older than 2 months of age as directed by the makers of the repellent and after discussion with your healthcare provider.
- Remove free standing water, old tires, and clutter from around the home and garage.
- Take steps to keep mosquitoes from entering the home.
- Using a mosquito net to cover babies younger than 2 months old in a carrier, stroller, or crib as directed by the maker of the product and under close supervision.
- Use protective intercourse every time with each encounter or abstinence.
- If you are considering planning a family; consult your healthcare provider.

If you think you are or have been infected by this virus seek medical advice from your local healthcare provider or emergency room.

Currently, there are no vaccines or special medications for the prevention or treatment of this virus. However, according to the National Institute of Allergy and Infectious Disease, researchers are currently conducting an investigational study on the safety and effectiveness of a possible vaccine in a small sample of healthy individuals in Atlanta, Georgia.

For additional information on the spread of this virus visit the Center for Disease Control and Prevention at: www.cdc.gov/zika.



Back to School

T'Shemika Perryman, RN - PACT Coordinator

It's back to school time kids!! School is in session!! Time to start waking up early and getting ready to learn! You'll be making new friends, meeting new teachers, and having a great time all while learning new and exciting things for the 2016-2017 school year. If you read, study hard, and do your work, you will be preparing yourself for a very successful year. Here are a few tips to help you start your journey:

- **Tip #1: Be prepared.** Being prepared for class not only means having pens, pencils, and paper, but also means reading all assignments at least once prior to attending class. This will help you retain the material being taught and also give you a chance to formulate any questions you may have.
- **Tip #2: Be organized.** This is so important to your being successful in the classroom. The key is to be able to find what you need with ease. Always keep your papers NEATLY organized in your folder or binder.
- **Tip #3: Maintain your attendance.** If you're not at school, you will not be prepared. If you are out of school with a medical illness, ask a friend about what was done in class or contact the teacher for missed assignments. Make sure you have a current chronic illness letter and updated medication lists on file in the office and with your teachers. Always take your medications as directed by your healthcare providers, drink plenty of water, and dress appropriately for the upcoming fall and winter seasons.
- **Tip #4: Take notes in class.** When you go home, read your assignments, study those notes, and you will most likely do well on your test. Also, if you don't know something in class, please ask questions, no matter how "dumb" you think it sounds, just do it. It will help you in the long run and maybe even one of your friends or classmates. I guarantee someone else wants to ask the same question but is afraid to do so.
- **Tip #5: Do your homework.** You should always do or attempt to complete your homework. No matter what. Homework recaps everything that was taught for that session and assesses your understanding of the material covered by your teacher. In addition, this gives you the opportunity to: (a) see your strengths and weaknesses; (b) determine what you need to focus on during your reading; and (c) identify questions you may need to ask the teacher the following day.
- **Tip #6: Plan to be successful.** If you have a large assignment or a project, start early. If you don't, you will have to cram everything in at the last minute. Proper planning will give you more time for: (a) mistakes that you can fix; (b) questions that you can ask and have

answered; and (c) time to gather additional information on your project. It will make the experience a lot less stressful. You'll also have plenty of time to make the project as good as it can be, and make a better grade, too.

These tips should help you make it through this school year successfully.

For those that may not have access to a computer or WiFi, we will be hosting the grand opening of the Learning Resource and Development Center (LRDC) on Monday, September 12, 2016 from 4pm-6pm located at 2451 Fillingim Street, MCSB 1515; Mobile, Alabama 36617. The LRDC has several laptop computers available for individual usage by participants of the Pediatric to Adult Care Transition (PACT) program, two 50" flat screen, smart TVs, and educational reading materials. These laptops can be used for school projects, resumes, to fill out college and job applications, etc. For additional information or to schedule an appointment to utilize the LRDC, please contact T'Shemika Perryman, RN at (251) 470-5875.

Congratulations to the High School Graduating Class of 2016 PACT program participants: Alasha Flott, Antwaun Kimbrough, Briah Sewell, and Lawrensha Williams. Congratulations are also in order for the successful transition of the following PACT program participants to the adult care team: JoMyron Brown, Janae Sanders, Tarane Robinson, Benita Ethridge, Raven Evans, and Demone Beard.



Dr. Johnson Haynes Jr., Director of the Comprehensive Sickle Cell Center and a Professor of Internal Medicine at the University of South Alabama College of Medicine, poses for a photo with Felix Simmons, President of the Classic Corvette Club of Mobile, AL (far left), club member Ronnie Pettway (second from left) and club vice president Steve Chumney (far right) Thursday, Aug. 25, 2016. The Classic Corvette Club of Mobile recently donated \$1,000 to the USA Comprehensive Sickle Cell Center.

The Big Surprise: Part I

Johnson Haynes, Jr., MD –Director, Comprehensive Sickle Cell Center

Isabella and Mike were childhood sweethearts. They had done everything together including college. There, Mike played wide receiver on the football team and Isabella was a cheerleader. They excelled in sports and their academics. Their lives were perfect, and they always knew that marriage was destined to be in their future. And of course there would be children, two boys and two girls, Mike would someday be a successful businessman, and Isabella would teach first grade. Being from good catholic families, they promised their parents there would be no sex until marriage. Their four years at the University passed quickly. On the day of their graduation, Isabella and Mike's families planned a big party for them. Their friends and families turned out in mass to participate in their celebration. What the couple had not shared with everyone was they had been offered jobs in Castle Rock, Colorado and yes, what everyone had anticipated, Isabella had accepted Mike's hand in marriage. When they made their big announcements, no one was surprised about their getting married but emotions were mixed about their leaving their home in Mississippi to take jobs in that foreign state, Colorado!!!! Despite the future move, everyone was happy that marriage was in the near future. Mike and Isabella were even happier that soon the one thing they had deferred would become a familiar place and time they frequently sought in the unification of their perfect love.

The wedding and consummation. With very little money, much optimism, and endless love, Isabella organized her team of family and friends to plan a wedding. Only two months to go before departing to Colorado and with only \$500 dollars, the wedding plans began. There was no cost for using the church where she and Mike were members since birth, Isabella would use her mother's wedding gown and Mike his father's tuxedo. They found simple, his and her wedding bands on Ebay for \$75. The Altar Guild provided flowers and guests were asked to bring their favorite dessert for the reception. Old Father Francis was just happy to marry them after watching them grow

up in the church. Mike's mom prepared her famous rum punch to cap things off. With everyone chipping in, Isabella was able to buy her wedding bouquet. This left them with \$350 for the honeymoon which would be in the town where they would begin their lives, Castle Rock, CO, population 45,000, elevation, 6500 ft. With only 5 days to go before departing, Mike and Isabella's wedding came off without a hitch and was the most beautiful wedding they had ever seen. While not the biggest, it was more than they could have ever hoped. They had planned to stay at the home of Mike's parents until their departure, but as luck would have it, they received a wedding gift for a 4 night free stay at the local Dewberry Inn. They felt so excited and nervous at the same time. The wedding ended and they were off to the Dewberry Inn. When they arrived they both were very tired but ready to become one in marriage and one, they became. It was more than they had ever imagined. It was true ecstasy. The next few days passed quickly as they loaded their old Chevy and prepared for the next phase of their new lives as husband and wife. The day of departure finally came and they left with all the hope, joy and promise needed to build a happy life together and hopefully a family one day.

The move to Colorado. Mike and Isabella started their journey to Castle Rock, CO, lunches packed, all the clothing they owed packed in three suitcases, along with lots of old photographs of their families and friends in Mississippi. To get them started in their new home, their parents paid a small moving company to deliver some old furniture they did not need. The trip was filled with many emotions but they knew together, they could do anything and everything would be all right. As they sojourned across Louisiana to Texas, New Mexico and finally crossing the Colorado state line twenty-two hours later, they were worn and relieved. The terrain had changed from what they had become so familiar with in Mississippi. They saw tumbleweed, prairie dogs, and antelope. There was little greenery, sparse trees,

and low mountainous ranges. And as they approached Castle Rock, they could see the Rocky Mountains. Finally they saw what they had been looking for, the sign, "Welcome to Castle Rock, Colorado."

The beginning of the mysterious abdominal pain. The morning following their arrival, the furniture was delivered. Now in their quaint little studio apartment, Mike and Isabella scurried around getting everything in place. "Wow, our first home, all tidy and neat." They were so proud, "Home at last." For the first time they had a chance to sit on their somewhat worn sofa. It seemed so comfortable, far beyond what they remembered when that same sofa set in Mike's parents basement. As they sat there reflecting over all that had happened in the last two months, college graduation, a wedding, a trip across country, their first apartment and don't forget, the feeling of true ecstasy, life was perfect. Now exhausted, they ventured to their own bed as husband and wife for the first time. They asked themselves, "How could being so tired, feel so good?" It took only seconds for them to fall peacefully asleep. What started as the perfect day and a peaceful nights' sleep came to a squeaking halt around 2:00 a.m. when Isabella awakened with a nagging pain just under the left side of her ribs. She tried not to disturb Mike, but after an hour or so of not getting any relief, she thought it best to wake him. Mike could see the concern in Isabella's face. He knew something was wrong. Rather than be sorry later, Mike said to Isabella, "We are going to the little Urgent Care Center we passed coming into town." While the Urgent Care Center was less than ten minutes away, it seemed much further. Isabella was so uncomfortable. Upon arrival she was seen right away. The doctor performed a seemingly thorough exam including some blood work. The only finding was Isabella had an anemia with small cells. As he explained this to them, Isabella told him she had had this as long as she could remember; her old doctor diagnosed her with iron deficiency and had her taking iron supplements. She always thought it

was related to her heavy menstrual cycles. He asked, "When was your last cycle," and she told him she was due a week ago but did not think much about being late when considering the recent stresses in their lives. The doctor thought it prudent to perform a pregnancy test before she was discharged. In the interim he gave her fluids and a mild pain killer and the pain slowly subsided as they patiently waited. An hour or so passed and the test results were in and yes, to their surprise, Isabella was pregnant! Their first thought was, "How could this be?" Their second thought was, "we know." The young, scared but happy couple was reassured that Isabella was ok but would need to make an appointment sooner rather than later to see Dr. Lorino, the only obstetrics doctor in town. Isabella now ok, both exhausted, they journeyed back to their new little home to rest. The following morning Isabella felt much better but still had some pain. While not sharing this with Mike, she made calling Dr. Lorino a priority to schedule an appointment. She was to be seen in ten days. This seemed a little long for Isabella but as the days passed, the pain subsided and she was back to her usual self after five or so days. Finally the day for her first prenatal visit came. Mike was more excited than Isabella and as usual, they both went to see Dr. Lorino. Their visit was uneventful and went well. Dr. Lorino had reviewed Isabella's record from her visit to the Urgent Care Center. His exam was equally benign and assured the young couple all was well and not to worry. With that reassurance, they left feeling good about the pregnancy. The days passed quickly. Mike worked hard at his new job as an accountant and Isabella her job as a first grade teacher. Over the ensuing months Isabella would have this recurring nagging pain under the left rib cage, nothing as bad as that initial episode. She would mention this to Dr. Lorino when he saw her but it was always attributed to the pregnancy. He noted that her blood count would periodically fall but thought this was also related to her being pregnant. At Isabella's 12 week checkup, the young couple was especially excited. Dr. Lorino was going to do an ultrasound to determine the gender of the baby. This proved to be a great day and the young couple was told, "It's a girl." Isabella had already anticipated this and had to Mike's surprise, already come up with a name. Their baby girl was going to

be called, Aria. The next six months just flew by. Other than an occasional mild pain under the left ribs, and early morning nausea, the pregnancy was a breeze until one evening about 7pm, Isabella's "water broke." Mike had been preparing for this, bags packed, gas in the car and all of the telephone numbers to family and friends back home in Mississippi programmed in his cell phone. Off they went to the hospital to meet their new daughter. Isabella stayed in labor for over eighteen hours. But finally, Aria arrived, 7lbs 6oz, 22 inches long. It was a miracle to Mike and Isabella. Ten fingers and toes, screaming to the top of her lungs as if to say, "Ready or not, here I come." The hospital stay was short-lived. After forty-eight hours, mama, baby and daddy were on their way home. As they entered the door of their little studio, Isabella thought, "I don't know how to take care of a baby." Mike felt the same but as usual, Mike had a plan. They had to survive for two days before the help arrived. Isabella's mother was on her way to help. That next two days were met with lots of diaper changes, frequent breast feeds, little sleep and more questions than answers. Finally the help arrived. Isabella and Mike were so glad to have the calm, experienced hand and heart of Isabella's mom during this somewhat overwhelming time. And like most grandmothers, she had decided she would have Aria call her, "Gammy."

The birth of Aria. Gammy's presence proved priceless. Isabella's confidence grew as she watched her mother care for Aria. There was calm in the midst of the endless demands of this innocent, beautiful little girl who had trouble distinguishing between night and day. A clear bond was being established between Isabella and Aria, a bond that only another mother could understand. For the first time, Mike felt a little uncomfortable or perhaps even a little jealous. Time that once was only shared between him and Isabella was now taken by Aria. He understood Aria's needs and Isabella's love but still that feeling was very real. As Mike had always done, he shared his feelings with Isabella. And as Isabella had always done, she assured Mike of her unconditional love for him. As life would have it, Aria woke up at 2:20 a.m. needing a diaper change and hungry and yes, Isabella was willing to share and allowed Mike to have the honor of changing Aria's diaper, feeding her and rocking her back

to sleep. Amazingly, for the first time Mike understood and the little "green-eyed monster" disappeared. As the next two weeks passed, Aria grew and grew; it was time for Gammy to return home, and for the new parents to face the beginning of the rest of their lives as a family, a team.

The confirmation that baby Aria has sickle cell trait. From the time of Aria's birth, every day brought a new adventure. She was full of personality and grew amazingly fast. A month had passed and it was now time for Aria's first visit with the pediatrician, Dr. Trammel. When Mike and Isabella walked into the office they beamed with pride as Mike held Aria. There were lots of new little people in the room and lots of crying as well but in spite of that, all was well. After about an hour they were called back to see the doctor. Aria passed her exam with flying colors and Mike and Isabella were so happy they had produced the perfect little girl. Dr. Trammel assured them they were doing a good job but there was one last thing they needed to discuss. She told the new parents that Aria's newborn screening test came back positive for sickle cell trait but not to worry it was not sickle cell disease. She went on to say that both parents needed to be tested because sickle cell trait is an inherited disorder and that one of them had to pass the gene to Aria. They were stunned. Emotions were mixed with feelings of guilt, sadness and confusion. Neither knew anything about sickle cell disease other than it was a disease seen in people of African ancestry and that neither of them was from that lineage. Or at least they had no knowledge of having African ancestry. They looked at each other as if to say, "Are we black?" Dr. Trammel explained to them that people of Mediterranean ancestry also can be carriers of the sickle cell gene. While this offered some relief, they felt guilty that one of them passed this gene on to their perfect little girl. Dr. Trammel reassured them again not to worry and that they should schedule an appointment with their doctor for testing. They accepted her suggestion and sojourned home in a bit of a fugue state. A day that started so perfect had ended with what now seems so bad.

The Big Surprise: Part II will be published in the 2017 April edition of *Sickle Cell Today*. Log on to <http://www.usahealthsystem.com/sicklecellcenter> to follow this story and to view other editions of *Sickle Cell Today*.



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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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