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Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center and Sickle Cell Disease Association of America-Mobile Chapter: Treasures for the Sickle Cell Community

By: Ardie Pack-Mabien, PhD, FNP-BC
Johnson Haynes Jr. MD Comprehensive Sickle Cell Center

The City of Mobile, Gulf Coast region and surrounding counties have a wealth of treasures. Among them are the Sickle Cell Disease Association of America (SCDAA), Mobile Chapter founded in 1976 and the University of South Alabama's Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center founded in 1980 at University Hospital, formerly the USA Medical Center.

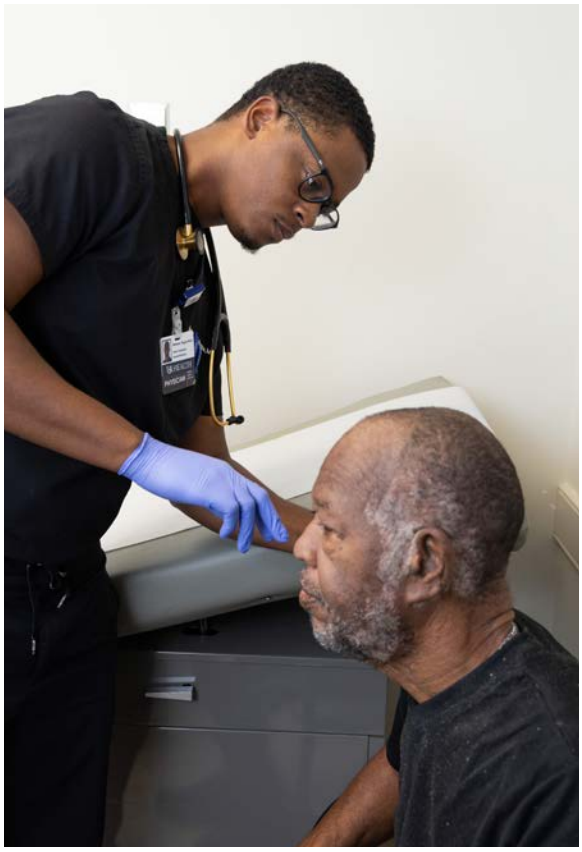
In 1981, the center and the local chapter collaborated to provide comprehensive services for individuals and their caregivers impacted by sickle cell disease (SCD).

Early on, the center was one of 10 federally funded comprehensive sickle cell centers by the National Institutes of Health in the United States. While the hospital provided the buildings and equipment, the center provided the scientists and knowledgeable providers for the medical management of individuals with SCD, and the SCDAA provided sickle cell trait counseling, psychosocial, after-school tutorial, and case management services.

In 2022, the USA Board of Trustees renamed it the Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center to recognize its namesakes 40-plus-year commitment to the university, center, and sickle cell community.

Though there is no longer federal funding, and the name and leadership have changed, the mission of the center and expertise of the providers remain unchanged. The center continues to provide consultation services for the diagnosis, management, and treatment of children and adults with SCD as far away as Montgomery, Alabama and along Gulf Coast region of Florida and Mississippi. Services are provided for an estimated 800 individuals.

The ongoing mission is to improve the lives of persons affected by this disease through comprehensive medical care by experts, clinical research, and community, patient, and professional education. In addition, it provides support for psychosocial issues that individuals affected by SCD may experience.



The center offers pediatric sickle cell care through the Department of Pediatric Hematology staffed by physicians, advance practice providers, and nurses at the Strada Patient Care Center located at 1601 Center St., Suite 1F. Behavioral health services and transition assistance from pediatric to adult care are also available for the pediatric population. The center has a pediatric to adult care transition program (PACT) that helps establish relationships with adolescents with SCD during their early teen years to prepare them for an effective transfer to adult care.

As participants of the PACT program, graduating seniors can apply for the Watson Henderson Higher

continued...

Achievement Award to support them in their education efforts after high school graduation.

Pediatric sickle cell care appointments are available two days a week.

Adult care services are provided under the Department of Internal Medicine, staffed by physicians, advance practice providers, and nurses, at the Mastin Patient Care Center located at 2451 University Hospital Dr., Suite 102.

Adult sickle cell care appointments are available four days a week. Both the adult and pediatric clinics are attended by the SCDAA, Mobile Chapter case manager and/or community health worker.

The center participates in clinical research studies that investigate potential new drug therapies that can be used to treat individuals with SCD and related disease complications. Teaching and continuing education are important to stay up to date on the latest treatment options.

Participation in the Sickle Cell Disease Practical Issues Regional Conference brings in nationally and locally recognized experts.

The faculty and staff of the center provide lectures for the SCDAA, Mobile Chapter nationally recognized certification program attended by nurses, social workers, case managers, and counselors across the United States.

Visit the Johnson Haynes Jr., MD Comprehensive Sickle Cell Center website to learn more about the center's services, sickle cell disease, and sickle cell trait at https://www.usahealthsystem.com/services/sickle-cell-care



The Beauty and Pain of Growing Older with Sickle Cell Disease

By Laventrice Ridgeway, Ed.D., ALC, Assistant Dean of Student Affairs, Whiddon College of Medicine, University of South Alabama

Growing older with sickle cell disease (SCD) was once just a dream. My grandmother was told at my birth that I would not live to see 19. But I never allowed SCD to direct my path. Instead, it was a driving force to be successful and accomplish my life objectives.

My grandmother's support is one reason I have such determination, so she deserves to be acknowledged. That, along with my faith and prioritizing my health, has given me confidence that I would defy the odds of living with SCD.

Finding the beauty of growing older with SCD requires rising above stigma, prejudice, and societal biases, and daring to overcome the odds. Daily, we dare to defy the statistics, and we learn to live with the added challenge of our disease.

So when one of us wins a personal battle over SCD, it's an inspiration to those who also struggle. I am a successful educationist, administrator, and community leader living with SCD. Every year, I gleefully celebrate my birthday as evidence of yet another triumph over the condition and a testament to the level of resilience I possess.

Despite the victories, it is exhausting and, at times, unrelenting. The jarring reality is that the disease is progressive, becoming worse with age and requiring increased intensity and vigor to fight back.

Medical advancements allow those with SCD to live longer, but it also reveals new complications. As an adult, I've had increased emergency department visits and hospital admissions, acute chest syndrome, splenomegaly (enlarged spleen), priapism, avascular necrosis, proteinuria, bone complications, increased sickle cell crises, as well as chronic and acute fatigue.

My most recent hospital admissions were back-to-back with complications that required taking family medical leave from work and having to request disability-related accommodations. In contrast, as a child, the most I had to deal with was an occasional crisis episode. The bulk of my health issues developed in adult life – understandable since SCD is progressive and can be distinctly challenging with age.

Balancing obligations to family, work, and oneself is what creates the foundation of a meaningful life. For an adult, managing the complications of SCD requires a comprehensive approach and a significant number of resources, finances, and support systems. If not managed appropriately in partnership with your sickle cell provider, the stress and pressure can and will have a deep impact on one's physical and mental health, an impact that, for those without a supportive work environment, could lead to job loss.

Often, I am used as an example of what successfully living with SCD looks like. Growing older with SCD is an ever-present possibility, but focusing on the positive minimizes the total experience.

Living with SCD requires attention to detail, from everyday activities to family planning. Longevity is a tribute to resilience and a reminder that continued support and understanding are vital.

The journey is demanding. I am privileged to have a strong familial support system. Unlike others with SCD, I am blessed with a supportive work environment where colleagues and supervisors prioritize my health and actively empower me to do what's best for me.

To all warriors, no one can face the challenges of SCD and transcend the way you do. Continue achieving and continue shining.



Helping Parents and Caregivers: Pediatric Sickle Cell Disease (SCD) and Pica

Jasmeka Foster, M.S.Doctoral Candidate, University of South Alabama,
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Pica, an eating disorder characterized by ingesting non-nutritive substances, can occur in both children and adults with and without sickle cell disease, and it can lead to various emotional issues.[1] Commonly ingested items include foam, hair, dirt, clay, chalk, paper, feces and ice.

Caregivers may notice the following:

- **Compulsive behaviors:** The persistent urge to consume non-food items, which result in significant stress and embarrassment, affecting self-esteem. Caregivers often realize later or find evidence that their child may be sneaking to eat non-nutritive items.
- **Nutritional deficiencies:** Health problems stemming from pica can exacerbate feelings of fatigue and malaise, impacting mental health.
- **Social challenges:** Pica behaviors may lead to social stigma and isolation.

One potential cause of pica in children with sickle cell disease (SCD) is nutritional deficiencies, particularly in iron and zinc.[2] Chronic anemia and other nutritional deficits can lead to cravings for non-nutritive substances. Iron is essential for growth and development, as it supports the production of hemoglobin, which carries oxygen in the blood, and myoglobin, which provides oxygen to muscles. Zinc is vital for immune function, metabolism, wound healing, and the senses of taste and smell. While a varied diet usually provides adequate zinc, deficiencies can occur due to inadequate dietary intake. Rich sources of zinc include chicken, red meat, and fortified breakfast cereals.

Chronic pain and medical challenges associated with pediatric SCD can contribute to psychological stress, potentially triggering pica behaviors as a coping mechanism.[3] Additional risk factors may include developmental problems (e.g., autism or intellectual disabilities) and stress from living in poverty, or experiences of abuse and neglect. Children with SCD might also come from environments where pica behaviors are more prevalent or culturally accepted.

Treatment of pica in children with SCD requires a multidisciplinary approach. It is necessary for parents and caregivers who notice symptoms of pica in their child with SCD to discuss them with the child's pediatrician, hematologist, or behavioral health provider. Managing pica in children with SCD involves comprehensive care, including behavioral interventions, nutritional counseling, support, and patient education.

From a behavioral health perspective, addressing both pediatric SCD and pica involves understanding the psychological, emotional, and social factors that affect children with these conditions. Both SCD and pica can significantly impact a child's mental health and overall well-being.

Behavioral Health Interventions:

- **Behavioral Therapy:** Therapeutic interventions like cognitive-behavioral therapy (CBT) can address the underlying psychological triggers of pica, teaching and helping children to develop healthier coping mechanisms.
- **Support Groups:** Participation in support groups can reduce feelings of isolation and provide emotional support from peers facing similar challenges.
- **Nutritional Counseling:** Speaking with a dietitian or medical provider helps to address any nutritional deficiencies that may be contributing to pica behaviors.
- **Environmental Modifications:** Ensuring that children do not have easy access to non-food items can help reduce the incidence of pica behaviors.
- **Parental Education**: Educating parents about pica and providing strategies enables parents to more effectively manage and monitor their child's behavior.
- **Pain and Stress Management:** Teaching youth techniques to manage both physical pain from SCD and the psychological stress can help avoid pica behavior triggering.

Comprehensive behavioral health interventions for managing pica in children with SCD involve several key strategies. First, integrated care teams, including pediatricians, hematologists, psychologists, nutritionists, and social workers, collaborate to provide holistic care. Regular monitoring of both physical and psychological symptoms ensures that emerging issues are promptly addressed. Also, offering resources and support to families helps them manage their child's complex needs. Education and empowerment play a crucial role, providing children and their families with knowledge about both SCD and pica, as well as effective management strategies.

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Buprenorphine Use in Sickle Cell Disease

Jessica King, FNP-BC, Johnson Haynes Jr. MD Comprehensive Sickle Cell Center

Acute pain arrives quickly and typically resolves within hours to a few days with the help of pain medications.

Chronic pain is present on most days, lasting over six months.[1]

Patients with chronic pain may not feel much pain relief, even with pain medications. By adulthood, over 55% of patients with SCD experience pain in over 50% of days; 29% experience pain 95% of days.[2]

To manage this, patients utilize a wide variety of analgesic medications, ranging from over-the-counter to prescribed controlled substances.

Unfortunately, individuals who endure frequent, severe pain crises are commonly treated with full-opioid agonist medications such as morphine, dilaudid, fentanyl, demerol, methadone, and oxycodone, which puts them at a significantly increased risk of developing tolerance of and/or physical dependence to these medications.

Buprenorphine is a medication that has been shown to provide pain relief with a significantly lower chance of these risks.[3] It was initially synthesized and discovered in 1966.[4] The medication was first U.S. Food and Drug Administration (FDA) approved for the management of acute pain in 1982, followed by subsequent FDA approval in 2010 for the management of chronic pain.[5, 6]

Buprenorphine works by activating the body's pain receptors less strongly, allowing the medication to provide pain relief while reducing cravings and withdrawal symptoms with less euphoria (intensified excitement and happiness) and sedating effects, compared with the previously mentioned full-opioid agonists.

Buprenorphine also helps to decrease the negative mood the body typically experiences during times of stress.[3]

Buprenorphine medication can be given in the form of a tablet, patch, or injection. The injection can only be given by a healthcare provider in a hospital or clinic setting where you can be closely monitored.

If the patient is determined to be a candidate to receive outpatient Buprenorphine therapy, the medication may be prescribed in a sublingual tablet form which is self-administered by the patient placed under the tongue to dissolve. It may also be prescribed in a self-administered transdermal patch form when the patch is applied to the skin.[7]

Follow these tips if Buprenorphine tablets or patches are prescribed to you:

Buprenorphine sublingual tablets:

- Place tablet under the tongue and let it dissolve. The medication will not work if swallowed.
- Only take one tablet at a time.[8]

Buprenorphine transdermal patch:

- Apply to clean dry skin to your upper arm or back.
- Alternate sites when you change your patch once a week.
- Cover with clear occlusive dressing, such as Tegaderm, while showering to keep the area clean/dry and to ensure continued medication effectiveness.
- Wash hands after application, and do not touch eyes.
- Store medication in a safe and secure place away from children and pets.
- If you go to the emergency room, inform your healthcare provider that you are taking this medication.[8]

Common side effects of buprenorphine include constipation, insomnia, headache, nausea, sedation, and dental health issues if using dissolving oral tablets.[9]

Listed below are some tips to assist with and avoid unwanted medication side effects.

- **Maintain good dental hygiene.** Notify your dentist if you are prescribed sublingual-dissolvable buprenorphine. Schedule and keep all dental cleaning appointments. If you are taking oral buprenorphine sublingual tablets, make sure to rinse your mouth out with water after the tablet has dissolved.
- **Avoid driving or operating heavy machinery** until you are aware of how the medication affects you.
- **Practice good sleep hygiene habits.** Turn off the TV or electronic devices in bed, avoid caffeine in the evenings, and maintain a regular nighttime routine.
- **Get adequate daily water and dietary fiber intake** to avoid medication-related constipation.[8]



As with any medication, please contact your healthcare provider or sickle cell specialist if you have questions or concerns about the medication being prescribed for the management of your SCD.

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Department of Education Guidance Highlights Academic Protections for Sickle Cell Disease: Update

Laventrice Ridgeway Ed.D., ALC, Assistant Dean of Student Affairs, Whiddon College of Medicine, University of South Alabama

New guidance from the U.S. Department of Education's Office for Civil Rights (OCR) has made a specific mention of educational protections for persons with sickle cell disease (SCD), interpreting it to be a disability qualified for academic modifications, accommodations, and auxiliary services based on the regulations of the Rehabilitation Act. Signed into law in 1973, the Rehabilitation Act stated, in part:

No otherwise qualified handicapped individual in the United States shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any programs or activity receiving Federal financial assistance. (34 C.F.R. Part 104.4)

Specific to education, Section 504 of the Rehabilitation Act (1973) requires that preschools, K-12 institutions, public and private universities or colleges, and other postsecondary organizations consider applications of qualified students regardless of their disability status, implementing any necessary disability-related accommodations and/or auxiliary aid (Madaus, 2011; Office of Civil Rights, 2024).

This new OCR guidance is significant to the process of requesting accommodations for persons with SCD because it highlights explicitly that SCD and its complication can potentially and/or substantially limit one or more major life functions such as cognition (i.e., concentration, thinking, and learning), breathing, walking, seeing, standing, and more related to complications of SCD. It also outlines that medical testing is only one of many ways to establish an SCD-based substantial limitation, giving the example that presenting a history of medical emergencies is appropriate and sufficient to chronicle SCD-related substantial limitations. Moreover, the OCR's 2024 guidance explicitly mentions scenarios in which SCD may impact a student's academic experience, which opens the door for considering tailored accommodations through an individualized and interactive request process.

With the OCR's 2024 guidance, students with SCD—as well as those in the professional setting—should perceive empowerment to seek the modifications, accommodations, and services required to promote their success. If you have questions or concerns about your child's performance in school, please discuss this with your school counselor or primary care providers, hematologist, or sickle cell provider at your next appointment.

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Pediatric to Adult Care Transition (PACT) Program: Open House Highlight

T'Shemika Perryman, RN, PACT Coordinator, Johnson Haynes Jr. MD Comprehensive Sickle Cell Center

The PACT program helps facilitate a seamless transfer between the pediatric and adult healthcare system, and ease fears associated with it. Parents and PACT program participants are invited to an annual open house at the Johnson Haynes, Jr., M.D. Comprehensive Sickle Cell Center to be educated on the process.

During last year's event, they met with adult healthcare providers, faculty, and staff of adult sickle cell care services, and toured the Mastin Patient Care Center and University Hospital, where patients will receive care at the age of 19.

Faculty, advance practice providers, and nursing staff from the Division of Pediatrics Hematology/Oncology, and the case manager and director of the Sickle Cell Disease Association of America, Mobile Chapter, also attend to address the psychosocial issues of transferring participants from the pediatric to adult healthcare system.

The 2023 event had the highest participation since the center's first open house in September 2017, with more than 25 patients, parents, family members, and providers.

Three adult clients, ranging in age from 35 to our oldest patient at 73, shared personal stories of fear, doubt, anger, rebellion, acceptance, and successes while living with the challenges of SCD.

They discussed dealing with peer pressure, the importance of routine medical follow-ups with their sickle cell provider and primary care provider, and challenges of adulthood, employment, and higher education.

PACT participants were inspired by their longevity and achievements. The faculty and staff of the sickle cell center express sincere gratitude to Mr. and Mrs. Fred Patterson, Ms. Kimberly Burden, and Laventrice Ridgeway, Ed.D, for taking time out of their busy schedule to share.

The open house included an overview of the transition process, differences between the pediatric and adult healthcare systems, and requirements for the Watson Henderson Higher Achievement Award with the PACT participants and their parents. The late Dr. Johnson Haynes Jr., M.D., was also remembered.

The faculty, and staff of the center were pleased with the success of the event, and they are enthusiastic about working diligently to keep this momentum going.

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USA Health and the local chapter of the Sickle Cell Disease Association established a partnership in 1981 to help educate the public and provide life-extending care to children and adults with sickle cell disease in the Mobile area, Gulf Coast and surrounding counties.

Mobile recognizes USA Health efforts during Sickle Cell Awareness Month

September is National Sickle Cell Awareness Month, and the City of Mobile recognized the observance.

Representatives of USA's Johnson Haynes Jr., M.D., Comprehensive Sickle Cell Center, including Ardie Pack-Mabien, Ph.D., FNP-BC, director, Antwan Hogue, M.D., medical director, and Hamayun Imran, M.D., division chief of pediatric hematology/oncology, received the proclamation from Mayor Sandy Stimpson during the city council meeting.

Many others from USA Health and the Sickle Cell Disease Association of America, Mobile Chapter were also present.

"We thank the Johnson Haynes Jr., M.D., Comprehensive Sickle Cell Center at the University of South Alabama, USA Health Department of Pediatrics Hematology/Oncology, and the Mobile Chapter of the Sickle Cell Disease Association of America for working to provide comprehensive care and support to sickle cell patients in Mobile," the proclamation read.

The sickle cell center, founded in 1980, and the local Sickle Cell Disease Association chapter, established in 1976, created a partnership in 1981.

"The Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center is a lifespan center, which uniquely offers both pediatric and adult sickle cell disease medical services, transition from pediatric to adult care, clinical research, and psychosocial support under one umbrella/entity by experts in the field of sickle cell disease," Pack-Mabien said.

The academic health system and the local sickle cell chapter work together to help educate the public and provide life-extending care to children and adults with sickle cell disease in the Mobile area, Gulf Coast and surrounding counties.

In addition to the proclamation, the lights of the RSA Tower in downtown Mobile were illuminated red on Sunday, Sept. 8, to recognize Sickle Cell Awareness Month.

"Both served to increase the public's awareness, knowledge, and understanding of sickle cell disease," Pack-Mabien said. "It recognizes and shines the light on the center's presence in the Mobile community and surrounding areas since 1980."