

Sickle Cell Today

VOL. 24, ISSUE 1

MARCH 2026

USA HEALTH
JOHNSON HAYNES JR., M.D.
COMPREHENSIVE SICKLE CELL CENTER

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Johnson Haynes Jr., M.D.
Comprehensive Sickle Cell

Center main office
251-470-5893
251-470-5895 fax

Pediatric clinic
251-405-5147

Adult clinic
251-470-5890

Community-based program
251-432-0301

Transition coordinator
251-470-5875

The long shadow of inequity in sickle cell disease

By Felicia Wilson, M.D., USA Health Department of Pediatrics, Hematologist/Oncologist and Professor of Pediatrics

Sickle cell disease (SCD) is the most common inherited blood disorder in the United States, yet progress has consistently lagged behind other genetic diseases. Its history is tied to systemic inequities. While the first case was reported by Dr. James Herrick in 1910, enslaved Africans were brought to the U.S. beginning in 1619 from regions where sickle cell trait was highly prevalent. Today, the Centers for Disease Control and Prevention estimates that more than 90% of the 100,000 Americans living with SCD are non-Hispanic Black or African American.

The lack of resources for SCD is stark when compared with other genetic disorders. Despite affecting fewer than half the number of individuals with SCD, both hemophilia and cystic fibrosis receive significantly more attention and funding. There are only 30 specialty centers for SCD, compared with 140 for hemophilia and 280 for cystic fibrosis. Cystic fibrosis receives 3.5 times the funding from the National Institutes of Health and a staggering 440 times the funding from national foundations.

Even when the National Heart, Lung, and Blood Institute recommendations were made, their implementation for SCD was slow. For example, newborn screening for SCD was recommended in 1987, but it took two decades—until 2006—for all 50 states to comply. Similarly, a 1997 recommendation for annual transcranial Doppler ultrasound screening for children to prevent stroke was made to enable early intervention. However, by 2019, only 33% of eligible children were receiving this critical screening.

The timeline for new treatments also reveals striking disparities. After the first drug, Hydroxyurea, was FDA-approved for adults in 1998, it was nearly 20 years before it was FDA-approved for children. In 2017, the second drug, L-glutamine, was FDA approved for children 5 years of age and older. In 2019, after the accelerated FDA approval of two new drugs, Crizanlizumab and Voxelotor, additional efficacy and



safety data emerged. Crizanlizumab was removed from European markets in 2023, and Voxelotor was removed from global markets in 2024, which highlighted the fragility of progress.

Despite these setbacks, the landscape for SCD is evolving. Stem cell transplantation, which emerged as a curative option in the 1990s, is now reporting success rates over 90%. However, its use is limited by challenges like finding a suitable donor, risk of graft-versus-host disease, transplant-related mortality, and potential long-term complications. Cautious optimism and excitement were generated in 2023 as

continued...

the FDA approved two gene therapies, Casgevy and Lyfgenia, to treat patients 12 years and older. Although these therapies offered a monumental step forward and a potential universal cure, their exorbitant price of over \$2 million per patient remains a significant barrier to widespread access.

Despite these advances, the average life expectancy for someone with SCD is still 30 years lower than the general population. Equalizing access to care and treatment to improve health outcomes in SCD is crucial and will require increasing provider knowledge and cultural competency, expanding access to comprehensive care, and advocating for more funding for research.

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Antibiotic stewardship in sickle cell disease

By Santosha Thompson, DNP-FNP-C, USA Health Johnson Haynes Jr., M.D.
Comprehensive Sickle Cell Center

Antibiotic resistance is one of the fastest-growing global threats to public health. Annually, resistant infections result in increased hospitalization rates, longer recovery periods, and higher fatality rates, especially among individuals who are immunocompromised. Individuals, including children and adults, with sickle cell disease (SCD) fall into this high-risk demographic due to compromised splenic function, heightened vulnerability to encapsulated microorganisms, and recurrent healthcare encounters.

In SCD, antibiotics are crucial and lifesaving. Penicillin prophylaxis has significantly lowered childhood deaths due to invasive pneumococcal infections. However, broad-spectrum antibiotics are still necessary during episodes of fever, sepsis, post-surgically, and when treating acute chest syndrome. Because of this, individuals with SCD are placed at a higher risk for antibiotic resistance. Infections become more difficult to treat when medications that were once reliable stop working, putting patients, especially young children and those recovering after splenectomy, at a greater risk for developing multi-drug-resistant infections.

This growing threat makes antibiotic stewardship not only a public health priority but also a critical patient-safety strategy for individuals living with SCD. The National Institutes of Health (NIH) emphasizes the importance of infection prevention and careful antibiotic management as essential components of high-quality SCD care.

Stewardship in this population ensures that antibiotics remain effective by focusing on several key principles listed below:

Using the appropriate antibiotic. American Society of Hematology (ASH) guidelines recommend penicillin for routine childhood prophylaxis in patients with HbSS or HbSβ⁰ thalassemia, rather than broader agents that increase resistance pressure.

Avoiding unnecessary antibiotic exposure.

Reduce inappropriate prescribing, such as administering antibiotics for viral respiratory symptoms, to conserve their efficacy for instances in which ASH guidelines recommend antibiotic utilization: fever assessment, suspected invasive bacterial infection, or surgical post-prophylaxis.

Ensuring adherence to vaccination

schedule. ASH strongly endorses adherence to pneumococcal, meningococcal, Hib, and

influenza vaccine schedules. Robust immunization reduces the incidence of invasive bacterial infections, thereby lowering the need for frequent or broad-spectrum antibiotic therapy.

Individualizing post-splenectomy

prophylaxis. ASH emphasizes the continued significant risk of overwhelming infection for people without functional splenic tissue. Depending on age, immunization status, and clinical risk, ASH guidelines recommend continuing antibiotic prophylaxis for at least one to three years post splenectomy. When risk is lower, stewardship entails offering sufficient protection while avoiding needlessly protracted therapy.

De-escalating broad-spectrum

antibiotics promptly. Once culture results or clinical improvement indicate that a narrower-spectrum antibiotic is appropriate, stepping down therapy helps reduce selection pressures and the development of antimicrobial resistance.

Antibiotic stewardship is an essential component of safe, evidence-based care for individuals with SCD. While preventive penicillin and early treatment of febrile illnesses have significantly reduced mortality, increasing antibiotic resistance undermines the efficacy of these life-saving treatments.

By adhering to ASH guidelines emphasizing targeted prophylaxis in early childhood, individualizing post-splenectomy protection, enhancing vaccination strategies, and minimizing unnecessary antibiotic utilization, clinicians can protect both immediate patient well-being and the sustainability of antimicrobial efficacy. Individuals with SCD and parents/caregivers of infants and children with SCD should present to and discuss with their sickle cell specialist, hematologist, or primary care provider the evaluation of febrile illnesses and indications for short-term and/or long-term use of antibiotics in the management of infections.

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Implications for immunizations in the management of individuals with sickle cell disease

By Amber Bokhari, Infectious Disease Physician, Assistant Professor, Hospital Infection Control Officer, USA Health University Hospital, and Biosafety Officer, University of South Alabama

Healthcare access is an area of grave concern for individuals with sickle cell disease (SCD). Sickled red blood cells die early and often become lodged in small blood vessels, restricting blood flow, which can lead to serious health problems throughout the body, including loss of splenic function, which is protective against encapsulated bacterial infections. SCD-associated complications include anemia, acute and chronic pain, infections, pneumonia and acute chest syndrome, stroke, and kidney, liver, and heart disease.

The National Institutes of Health (NIH) recommends medical screenings and interventions to prevent or reduce complications of SCD, including getting all childhood vaccinations and additional vaccinations. People with SCD, especially infants and children, are more likely to experience harmful infections, such as the flu, meningitis, and pneumonia. Pneumonia is a leading cause of death in infants and young children with SCD. Individuals with SCD who require regular transfusions as part of their treatment are also at increased risk for viral hepatitis. The Centers for Disease Control and Prevention (CDC) recommends receiving all routine childhood vaccinations in individuals with SCD, as well as specialized vaccinations including influenza, COVID-19, and pneumococcal and meningococcal vaccines to prevent serious infections due to immunocompromised state and risk of infection with capsulated bacteria due to functional asplenia.

It is pertinent to remember that immune response may be suboptimal in SCD due to an immunocompromised state and may need monitoring with serology to confirm the patient has an adequate antibody response for protection against subsequent infection. Individuals with SCD may need boosters, an extra dose of the vaccine, after initial vaccination to mount an adequate response. Childhood survival rates have increased with the universal use of pneumococcal and other routine vaccines. It is important to note that the first pneumococcal vaccine decreased the rate of pneumococcal infection in children with SCD under 3 years of age by more than 90 percent (Obeagu, E. & Obeagu, G. 2024).

The latest data continues to show that individuals with SCD have an increased vulnerability to severe COVID. It has also been noted that COVID can trigger SCD symptoms like vaso-occlusive pain or acute chest syndrome.

The Sickle Cell Disease Association (SCDAA) Medical and Research Advisory Committee (MARAC) strongly urges individuals with SCD and their families to get vaccinated and get all recommended boosters.

Essential vaccines for individuals with SCD after routine childhood vaccinations are as follows:

Pneumococcal: Protects against pneumonia. The American Academy of Pediatrics recommends a complete pneumococcal conjugate vaccine series (PCV15 or PCV20) before age 6 and then one dose of PCV20 vaccine from age 6 to 18. Catchup dosing recommendations are available for children who have not completed the initial vaccine series.

Hib (Haemophilus influenzae type b): Prevents meningitis. It is recommended as Hib-MenCY at 2, 4, 6 months and 12-15 months. Children between 2 months to 6 years of age require a booster every five years starting after 3 years of primary immunization. After 7 years of age, they need a booster every five years starting at 5 years after primary immunization. Hib vaccine is given as a single dose for patients who have not previously received it.

Meningococcal: Protects against meningitis. Meningococcal conjugate vaccine for serotype A,C,W,Y given at younger age and serotype B given after 10 years of age with subsequent boosters three years after the initial vaccine, then every five years.

Influenza (Flu): Annual vaccination is strongly recommended.

Hepatitis A & B: Protects against liver infection due to high risk of Hepatitis B which is indicated with frequent transfusions and immune dysfunction. Hepatitis A is important in travel to endemic areas.

COVID-19: prevents infection in high-risk individuals.



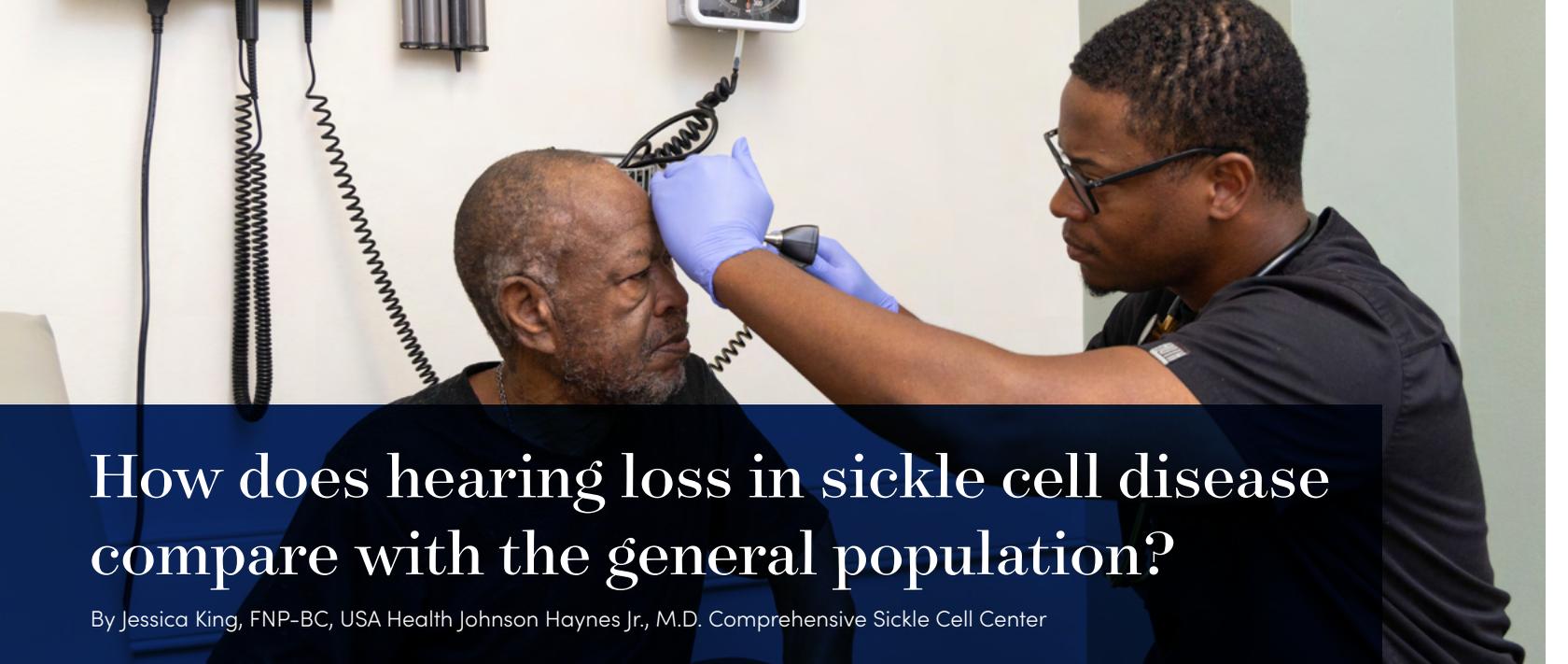
Management of SCD is focused on preventing and treating pain episodes and other complications. Prevention strategies include lifestyle behaviors as well as medical screening and interventions to prevent SCD complications. Tips to prevent harmful infection include:

- Frequent hand washing by individuals with SCD and their family/caregiver with soap and water for at least 20 seconds.
- Use hand sanitizer if you are not able to wash hands.
- Safe food preparation, cooking, and/or handling.
- Practice proper respiratory etiquette by covering your mouth when you sneeze or cough.
- Keep wound(s) clean and covered as directed by your provider.
- Avoid contact with individuals who are sick or contagious.

Follow up and consult with your primary care provider and/or sickle cell provider/hematologist routinely for shared decision-making discussions on your potential benefits and risks.

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How does hearing loss in sickle cell disease compare with the general population?

By Jessica King, FNP-BC, USA Health Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center

Sickle cell disease (SCD) is a group of inherited blood disorders characterized by abnormal hemoglobin S (HbS), which causes red blood cells to become rigid and sickle-shaped. These changes can result in vaso-occlusion, chronic anemia, and progressive end-organ damage. The auditory system is particularly vulnerable to vaso-occlusive events due to its sensitivity to reduced blood flow and oxygenation (Kiser, 2019). While complications such as vaso-occlusive crises, acute chest syndrome, and stroke are well documented, the association between SCD and hearing loss has gained increasing attention. This article aims to help the general population better understand hearing loss within the SCD community and how it differs from hearing loss in the general population.

Hearing loss is common in the general population and is often associated with aging. In the United States, leading causes include age-related changes, noise exposure, and genetics. Additional contributing factors include infections, head injury, stroke, diabetes, tumors, autoimmune disorders, earwax blockage, and ototoxic medications (National Academies of Sciences, Engineering, and Medicine, 2016).

According to the National Institute on Deafness and Other Communication Disorders (NIDCD), approximately 28.8 million U.S. adults could benefit from hearing aids. Research indicates a disproportionately higher prevalence of hearing loss among individuals with SCD (Laredo, Torres-Small, Wu, Makishima, & Richard, 2024), with reported rates ranging from 12% to 66% (Farrell, 2019).

Hearing loss in SCD is believed to result primarily from micro-vaso-occlusive events that reduce blood flow and oxygen to the inner ear. Secondary contributors include

increased susceptibility to infections such as meningitis and otitis media, exposure to ototoxic antibiotics, and potential side effects of iron chelation therapy used in patients requiring chronic transfusions (Strum, MD, et al., 2021). Opioids commonly prescribed for vaso-occlusive pain have also been associated with reported cases of sudden or progressive hearing loss (Speller-Brown et al., 2022).

Common symptoms of hearing loss include difficulty hearing conversations, especially in noisy environments; increasing television or radio volume; asking for repetition; ringing or fullness in the ears; dizziness; fatigue from listening; and social withdrawal.

Hearing loss is often underrecognized and diagnosed later in its course. Early identification is especially important in children, given the impact on speech, language development, academic performance, and social well-being. Outside of newborn screening, routine audiograms are not consistently performed in patients with SCD. Regular hearing evaluations are recommended, particularly before and after initiating new treatments (Strum, MD, et al., 2021; Youner, 2026).

In adults, hearing loss can significantly affect employment and communication, underscoring the need for provider awareness and screening (Kiser, 2019). Notably, Alabama Medicaid does not cover audiogram screening after age 20 (Alabama Medicaid Agency, n.d.). Alabama residents are encouraged to coordinate care with their healthcare provider, audiologist, and the Alabama Chapter of the Sickle Cell Disease Association of America for potential financial assistance.

Individuals with concerns about hearing changes should consult their sickle cell provider, hematologist, or primary care provider for evaluation and guidance.

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Sickle Cell Disease Practical Issues XIX: Nurses, Anchors of Healthcare in Sickle Cell Disease highlights

Ardie Pack-Mabien, PhD., FNP-BC, USA Health Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center Director

“Excellent, informative, in-depth program—I will be back next year” is how several attendees described the Annual Sickle Cell Regional Conference. For the first time in its 19-year history, the conference had a dedicated focus on nursing education. In previous years, the conference primarily emphasized physician continuing education, but it was consistently supported by strong attendance from USA Health nurses. In recognition of this long-standing support, continuing education credits, conference materials, meals, and gifts were provided at no cost to USA Health nurses and allied health professionals.

The USA Health Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center has a mission to improve the lives of individuals affected by sickle cell disease (SCD) through comprehensive clinical care, research, and education. To support this mission, it hosts an annual regional conference addressing practical issues in SCD care, offering the latest evidence-based treatment strategies, management of complications, and psychosocial considerations.

This year’s conference brought together six physicians and approximately 40 physician assistants, nurse practitioners, registered and licensed practical nurses, pharmacists, social workers, community health workers, allied health professionals, and students. Attendees received 6.3 continuing education credits. The program opened with a brief slideshow highlighting the center’s medical, educational, and community outreach efforts, concluding with a tribute to the late Dr. Haynes Jr., honoring his 42 years of service to the University of South Alabama and the sickle cell community.

The conference featured nationally and locally recognized experts dedicated to advancing SCD care. The Dr. Cecil Parker Distinguished Lectureship was delivered by Felicia Wilson, M.D., a pediatric hematologist/oncologist at USA Health and professor in the Whiddon College

of Medicine. She opened the conference with a presentation on the pathophysiology of SCD.

Additional speakers from the University of South Alabama included Antwan J. Hogue, M.D.; Hamayun Imran, M.D.; Jennifer Williams, CRNP; and Jessica King, FNP-C. Dr. Hogue, hospitalist and medical director of the center, discussed precision medicine and individualized inpatient care planning for patients experiencing sickle cell pain crises. Dr. Imran, division chief of pediatric hematology/oncology, presented on gene therapy, sharing the journey of a current recipient and highlighting its potential as a transformative treatment option.

Williams addressed age-appropriate education in pediatric SCD management, while King concluded the conference with an evidence-based discussion on inpatient nursing care for adults with SCD. Both nursing presentations offered practical guidance applicable at the bedside.

Mohammad Barouqa, M.D., assistant professor of pathology and director of blood bank services at USA Health, was recognized for exemplary transfusion medicine services and dedication to individuals with SCD. Special recognition was also given to T’Shemika Perryman, RN, and Jessica King, FNP-C, for their years of outstanding service to the center and patients with SCD.

The conference offered interactive sessions and networking opportunities. Special thanks to USA Health System, Novo Nordisk Inc., Chiesi USA, and Gulf Coast Total Care for their financial support, which helps keep registration affordable and sustains ongoing educational efforts.

To be added to the mailing list for future conferences, contact the center at 251-470-5893.



Sickle Cell Awareness Month celebrated with special honors, expanded outreach, and growing momentum

By Gerald Alfred, Executive Director, Sickle Cell Disease Association of America – Mobile Chapter Executive Director

This year marked one of the chapter's most active and engaged observances yet, featuring major community events, expanded outreach, new partnerships, and two standout moments that underscored the chapter's growing national presence.

Stone honored with 2025 National Sickle Cell Disease 53rd Annual Convention POWER Award

Chondra Stone received the National Sickle Cell Disease Association of America's 2025 POWER Award, one of the highest honors given to a community health worker (CHW) serving individuals with SCD. It recognizes a CHW who demonstrates compassion, leadership, and service that exceeds expectations.

Stone has played a critical role in strengthening SCDA-MC's presence across Mobile and Baldwin counties. She leads outreach events, supports families during crisis moments, and helps individuals with SCD navigate daily challenges associated with their disease.

Alfred highlights growth and impact of BeHEARD Footprint

Executive director Gerald Alfred—one of three community-based organization directors selected out of 57—had the opportunity to present his signature outreach and engagement model at the 2025 Empowerment Conference, held during the 53rd National SCDA Convention in Rosemont, Illinois.

BeHEARD represents: Bridging Education, Hope, Empowerment, Advocacy, Research, and Dedication. The BeHEARD footprint has grown into one of the most comprehensive sickle cell outreach infrastructures in the region, now gaining national attention as a promising model for community-based organizations across the country. This initiative currently spans nine Alabama counties, providing: increased testing access; transportation assistance for medical appointments; community health worker support for families; stronger connections with health-care providers and schools; and more.

Sickle Cell Awareness Month: A month of impact and community engagement

SCDA-MC and USA Health Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center hosted and supported these major activities during the month of September:

- SCDA-MC / Cumulus Broadcasting Radiothon to spread awareness.
- Shine the Light UnGala to honor survivors, caregivers, and supporters.
- TriSickle for SCD Awareness to educate the community on SCD, and to promote health, movement, and community engagement.
- Lighting of the RSA Tower to recognize SCD in the city of Mobile.
- City of Mobile Proclamation to officially honor September as Sickle Cell Awareness Month.
- SCDA-MC Open House to welcome families, partners, and new supporters.
- Johnson Haynes, Jr., MD CSCC Pediatric to Adult Care Transition (PACT) program open house to introduce adult SCD providers to transitioning young adults and their families.
- Sickle cell trait testing services to increase early detection and education.
- Alpha Phi Alpha Fraternity, Inc. Annual Blood Drive to support the urgent need for blood donations, where 45 units of blood were collected, impacting the lives of 135 individuals.



New pilot program to help during sickle cell pain crises

Living with sickle cell disease means acute pain episodes—called pain crises—can happen without warning and often lead to emergency care. A new pilot program from the Sickle Cell Disease Association of America (SCDA) and the MedicAlert Foundation offers a simple tool that could make a big difference during those critical moments: a Smart Medical ID Card.

Here's how it helps:

Shares important health information instantly.

Participants complete a digital health profile that includes their physician-approved pain plan, hematologist contact, medications, allergies, and other essential details. Emergency staff can view all of this simply by scanning a QR code on the ID card—no more waiting while vital information is tracked down.

Designed to speed care. The goal is to help emergency departments act faster and more confidently, especially in pain crises when time matters. Emergency personnel can immediately see the patient's history and care plan, helping reduce delays and miscommunication.

Free for eligible adults. Adults (age 18+) in the U.S. with a confirmed sickle cell diagnosis can participate at no charge. The program provides the card and a one-year protection plan while collecting feedback to improve emergency care practices.

Tip: If you or someone you care for has sickle cell disease, consider enrolling or sharing this information with your care team. A simple QR scan could mean quicker, more informed emergency care when it's needed most!

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Return this form and payment to: USA Health Development
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Thank you for your consideration.



Welcome Victoria McGuire to the USA Health Sickle Cell Center

Victoria McGuire brings a strong background in administrative support, public service, and organizational leadership to her role as the newest administrative assistant for the USA Health Johnson Haynes Jr., M.D. Comprehensive Sickle Cell Center.

“I was drawn to this role because it allows me to contribute to something that truly matters,” she said. “I wanted to work in an environment where my day-to-day efforts help patients and families feel supported, welcomed, and understood. “Using my administrative and organizational skills to support the team and help the center run smoothly felt like a natural fit.”

She is excited to be part of the culture and commitment she observed immediately when she joined the staff. “From the moment I walked in, it was clear how dedicated everyone is to the mission,” she said. “Being part of a team that shows up every day ready to make a meaningful difference is incredibly motivating.”

She is also eager to grow professionally in an environment that values collaboration and purpose. “I’m excited to learn alongside colleagues who truly care about their work. It’s rewarding to know that what I do matters and contributes to something bigger than myself.”

One aspect of the center that stands out is its holistic approach to care. She is particularly inspired by the Pediatric to Adult Care Transition (PACT) program, which supports young patients with sickle cell disease as they move into adult care services. “The center’s focus on improving quality of life, expanding education, and treating patients as whole people is something I truly admire,” she said.

In her role, McGuire will support daily operations while helping create a positive, welcoming experience for patients, families, and staff.