Sickle Cell Today

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

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Main office
251-470-5893
251-470-5895 fax

Clinical research
251-471-7703

Pediatric clinic
251-405-5147

Adult clinic
251-470-5890

Community-based program
251-432-0301

Transition coordinator
251-470-5875

Sickle Cell Disease Awareness: General Information and Relevant Facts

Ardie Pack-Mabien, Ph.D., FNP-BC, Antwan Hogue, M.D., & Felicia L. Wilson, M.D., FAAP

First identified in 1910, sickle cell disease (SCD) is a hereditary hematological disorder affecting approximately 20 million people worldwide and is most common in African, Mediterranean, and Arabian Peninsula areas.[1] However, there is not a reliable, global estimate of affected individuals, but newborn estimates consistently suggest that approximately 300,000 babies are born annually with SCD, of which at least 75% are in Africa. SCD has long been misconstrued as a "Black disease" or a disease of racially marginalized groups, and this racialized notion of the disease is a key element of its distinctive biocultural story.[2]

As one of the most notable hereditary diseases in the world, SCD is estimated to affect more than 100,000 individuals in the United States. Since the early 1970s, the federal government has conducted a National Sickle Cell Disease Program. Coordinated by the National Heart, Lung, and Blood Institute, it promotes efforts toward prevention, diagnosis and treatment of this disease. The introduction of newborn screening for early diagnosis and prevention with prophylactic penicillin is arguably the biggest advancement in the care of infants and children with SCD. Here in the state of Alabama, estimates indicate SCD affects approximately 2,500 individuals. Each year in our state, the newborn screening program diagnoses 50 to 60 newborns with SCD and approximately 1,800 to 2,000 newborns with sickle cell trait. The table shows the races reported of the 1,788 newborns diagnosed with sickle cell trait by the Alabama Newborn Screening Program in 2022.

Alabama Newborns with Sickle Cell Trait by Race in 2022

Asian	1
Bi-racial	4
Other	23
Hispanic	33
White	184
African American	1,501
Not reported	42

By the mid-1970s, the National Association for Sickle Cell Disease, Inc. created and launched a series of SCD awareness campaigns nationally. The focus of this month-long campaign, launched in September 1976, was to address the growing concerns about misinformation on SCD and to provide education. Then in 1983, the Congressional Black Caucus of the U.S. House of Representatives passed a resolution. This resolution asked then-President Ronald Reagan to proclaim September National Sickle Cell Anemia Awareness Month. President Reagan signed this proclamation (named 5102) in September 1983.

In an effort to raise awareness of SCD globally, the United Nations General Assembly adopted a resolution in December 2008 that recognized SCD as a public health problem nationally and internationally. The resolution urged members of the United Nations to spread awareness about SCD every year at the national and international levels and officially designated June 19 as World Sickle Cell Awareness Day, the goal of which was to increase public knowledge and understanding of SCD and the challenges individuals and their families and/or caregivers experience daily. The first World Sickle Cell Day was on June 19, 2009.

Over the years, there has been substantial and ongoing progress in research on SCD, and diagnostic imaging has greatly improved. However, there are

continued...

currently only four disease-modifying therapies approved by the Food and Drug Administration (FDA) for the management and treatment of SCD. To date, bone marrow or stem cell transplantation remains the only FDA-approved treatment for a cure. However, access is limited for many of the individuals with SCD because transplantation can come with serious risks, require a close donor match, and is only used in severe cases.

Although there have been accomplishments over the years in terms of sickle cell awareness campaigns and research, much more remains to be done to conquer this serious health problem.

As we enter the month of June, here are a few facts about SCD:

- SCD occurs in about one out of every 365 African American or Black births.
- About 1 in 13 African American or Black babies are born with SCD.
- SCD can affect individuals who are not African American or Black.
- Because of abnormal hemoglobin, red blood cells stick together and create a "sickle" or crescent shape, which causes acute and/or chronic pain and other related health complications.
- Bone marrow transplantation is the only FDA-approved potential cure for SCD.

Let us take time to recognize the perseverance of individuals living with SCD and to recommit ourselves to improving their quality of life and health outcomes.

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www.sicklecelldisease.org/get-involved/events/awareness-month-and-world-sickle-day/

www.nhlbi.nih.gov/education/sickle-cell-month

www.reaganlibrary.gov/archives/speech/proclamation-5102-national-sickle-cell-anemia-awareness-month-1983

Medication Shortage and Helpful Tips

Jessica King, FNP-BC

Recently there has been a limited availability of over-the-counter medications, such as pediatric Motrin and Tylenol, attributed to the rise of flu and a spike in other respiratory viruses. Some other medications that are in short supply include the antibiotic Amoxicillin, bronchodilators, or asthma medication known as Albuterol, and certain medications used to treat diabetes, obesity, and certain cardiovascular diseases. Overall, the causes of medication shortages are multifactorial and often depend on the type of medication[1]. Factors attributing to the shortage of these medications include difficulties in acquiring raw materials, manufacturing problems, production delays, regulatory issues, and business decisions, as well as many other disturbances within the supply chain[2]. Nonetheless, whatever the cause of a medication shortage, it is frustrating to everyone involved, including patients.

Here are some helpful tips on dealing with medication shortages:

- **Don't wait until your prescribed medication has run out to request a refill.**
- **Factor in time to get a refill due to potential medication shortages.**
- **Request that your healthcare provider provide a printed prescription in case the first pharmacy you go to doesn't have it.**
- **Contact your healthcare provider or pharmacist to see if a similar medication is available when a medication you have been prescribed isn't available at your local pharmacies.**
- **Stock up and keep a small supply of commonly used over-the-counter medications such as Tylenol and Motrin for anticipated needs.**
- **Obtain the recommended annual influenza and COVID-19 booster immunizations.**

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The Importance of Vaccination in Children with Sickle Cell Disease

Jennifer Williams, C.R.N.P., and Mikayla Johnson, PA-C
Department of Pediatrics, Hematology/Oncology

Vaccines stimulate the immune system to produce antibodies, just as it would if the child were exposed to the disease. Vaccines contain the same antigen proteins that are in a specific bacterium or virus. Antigens either kill or weaken the bacteria or virus to the point that they do not make you sick yet develop enough immune response leading to sufficient antibody protection against the disease. Vaccines are safer for children than their first exposure to a disease; the child can develop immunity without suffering from the actual disease.

Children with sickle cell disease (SCD) are at an increased risk of infections due to the decreased function of the spleen. The pneumococcal vaccine, introduced in 2000, led to a 42% decrease in SCD-related death in African American children younger than the age of 4 from 1992 through 2002.[1] Getting all routine childhood vaccines, including annual influenza (flu) and COVID-19 age-specific vaccines, is highly recommended.

The Centers for Disease Control (CDC) recommends flu shots for all children ages 6 months and older by the end of October each year. Evidence shows it reduces the risk of flu by 40-60%. It doesn't prevent getting the flu; but studies have shown it can decrease severity. A 2021 CDC study found patients vaccinated against flu had a 26% lower risk of admission to the ICU for flu-related complications and a 31% lower risk of death.[1]

In 2019, there were an estimated 113 more SCD-related deaths in 2020 than expected based on the historic SCD-related death rate.[2] COVID-19 was listed as a cause of death for 86 (8.4%) SCD-related deaths reported in 2020.[3] Like other immunocompromised patients, individuals with impaired splenic function should receive three doses of the mRNA COVID-19 vaccine, as well as the COVID-19 bivalent booster.[4]

In the early 1980s, Hib was responsible for an estimated 2 to 3 million cases of serious diseases including death, with a four-fold increased risk of H influenza septicemia in children under 9 with SCD. The conjugate Hib vaccine in 1987 significantly decreased the incidence of invasive Hib infections. A study at Children's Hospital of Philadelphia revealed zero cases of H influenza bacteremia among them after receiving the Hib vaccine from 2000-2010 out of 815 children with SCD.[4]

An Active Bacteria Core surveillance study from 1998-2009 found a greatly reduced incidence of invasive pneumococcal disease (IPD) in children with SCD after the introduction of the 7-valent pneumococcal conjugate vaccine (in addition to penicillin prophylaxis) in 2000.[5] Despite this, children with SCD remain at a significantly higher risk of contracting IPD compared to the general African American pediatric population. For children with SCD, the CDC also recommends an additional two doses of PPSV23.

Evidence exists that children with SCD are at a 300 times greater risk of developing bacterial meningitis. The Advisory Committee on Immunization Practices (ACIP) found that in children with functional asplenia, meningococcal vaccines have the lowest adherence rate, with only 25% of these children receiving it.[6] For those at increased risk of infection, such as children with SCD, MenACWY vaccines are recommended to be given as early as 2 months old.[7]

Unvaccinated children have a greater risk of getting diseases that otherwise could be prevented. They also put parents, family members, and the community at risk for disease, especially those with weakened immune systems, such as children too young for vaccination and people who cannot have vaccines due to medical reasons.

Multiple barriers to vaccination exist, including patient and caregiver knowledge. A National Network for Immunization Information survey of 1,600 parents found they wanted more information about how immunizations work, side effects, and guideline recommendations.[8] Better communication with primary care providers and hematologists, as well increased awareness and education of the vaccines recommended for SCD patients is needed.[9]

Vaccination-schedule-related barriers include lack of knowledge/awareness of the schedule, forgetting immunizations are due, and not remembering appointments. Inaccurate or misleading information from other sources, such as media or personal-information-seeking, were also identified.[10] Overall, good patient/provider relationships with open communication and understanding lead to better care. Having sickle cell disease can cause many complications that could be worse without understanding how vaccines work to prevent them. The ongoing discussion of vaccines among patients, families, and providers is of utmost importance in protecting an SCD patient's health.

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cdc.gov/vaccines/vpd/mening/hcp/recommendations.html

Grieving and Loss: A Caregiver's Guide

Katey Hayes, M.S., Jasmin Pizer, M.S., & Jasmaka Foster, M.S., University of South Alabama Psychology Department

Children with sickle cell disease (SCD) can experience different kinds of grief, from feelings that they will never be "normal" due to having a chronic illness, missing school, not being able to participate in extracurricular activities or day-to-day activities of childhood, unlike their sibling or classmates, or the loss of a friend or loved one. The loss of a loved one may be related to SCD, another chronic illness, or violence. Regardless of the circumstances surrounding the loss, there is often a concern by caregivers about how to address their grieving child, answer their child's questions, and tell their child the "right" answer. There is no perfect response to grief. Additionally, it is important to understand that everyone mourns differently, and depending on your child's developmental level, he or she may respond differently. This guide will provide those who love a child with sickle cell disease some age-specific behaviors and tools to understand their grief and help the caregiver(s) to respond in a way that will help your child through the grieving process.

Because children **ages 2 to 4** struggle to understand the permanence of death, they may ask you the same question multiple times. Grief may present in other ways such as a regression in behaviors. Children at this age may begin thumb-sucking, acting clingy, acting out, or being irritable. You can help children at this age cope with grief by offering a lot of reassurance, maintaining a consistent routine, and allowing them space to play.

Expect curiosity and many questions about death from children **ages 4 to 7**. It is important to answer these questions honestly and not avoid the topic. Create a safe space for them to ask as many questions as they have. It is also important to discuss the difference between what led to the death and what did not. This discussion is helpful for a child with a chronic illness to prevent inaccurate associations between feeling sick and death. Grief may be expressed through nightmares, changes in behavior, and role-playing as the individual who died. Encourage their expression of grief through helping the child identify their emotions, allowing them to feel these emotions, and relieve these emotions through physical activity, drawing, and storytelling.

Between ages 7 and 13, you may start to notice your child's increased maturity surrounding death. School-age children grieving the loss of a loved one are inquisitive, so be prepared for questions that require details from caregivers. Children may become fearful and fixated on the way a person died. They may not fully understand the cause of death, and essentially need assistance from the caregiver to provide them with an explanation that makes sense. As they grow older, they will be better able to understand the underlying mechanisms of death. Common behaviors and/or expressions to expect are an increase in school concerns, withdrawal from social life, acting out, changes in eating and sleeping, and thoughts about their death. Caregivers can offer a safe space to encourage the child to express their feelings. Lastly, do not avoid speaking about death. A conversation about death can help the child process their thoughts and feelings more accurately.

Teenagers **ages 13 to 18** may express their grief through seclusion, sadness, defiance and risk-taking. Encourage these teenagers to speak with you, a friend or a professional. If they are unwilling to speak with you, it is important to spend time with them regardless. Simply spending five minutes per day with them will help build trust and create a supportive environment. During these five minutes, follow the teenager's lead. If they would like to remain quiet, sit in that silence with them. It is important to engage in an activity together that can promote conversation, such as taking a walk, drawing, or constructing/building.

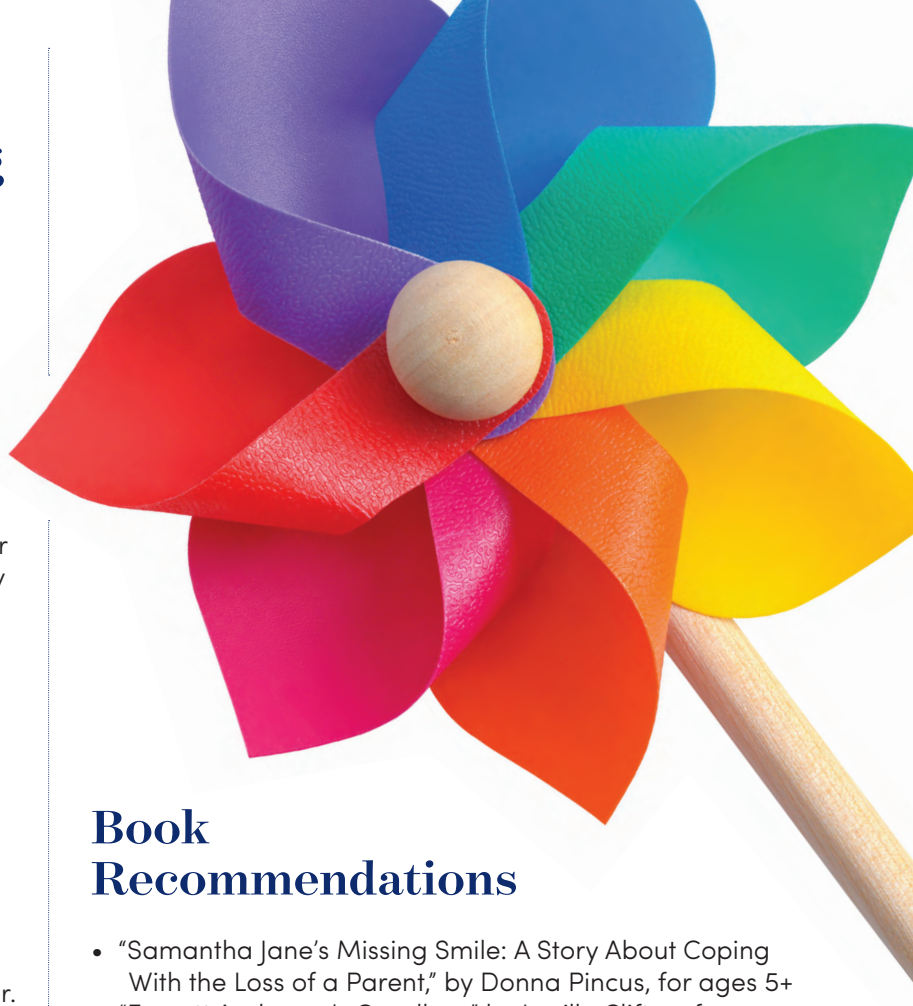
Activities to Promote Healing in the Grieving Child:

- Emotions calendar
  - Create different emotions and a calendar, and allow the child to pick out how they are feeling each day of the week and discuss their response with them.
- Feeling jar/mailbox
  - Create a jar/mailbox where the child can draw/write any questions/comments/feelings they are having on a piece of paper. This piece of paper gets put into the box and gets discussed at a family meeting that happens at the same time each day/ week, etc.
- Encourage journaling
  - Provide your child with encouraging prompts in a journal of their choice.
  - Create a family scrapbook, which could include pictures, notes to one another, important quotes and so on.
- Take 10 slow breaths
  - Using pinwheels or bubbles to practice deep breathing can be helpful for younger children.
- Get moving
  - Create a family playlist and move to music together.
  - Stomp on the ground or bubble wrap.
  - Plant a tree/flower in remembrance of the loved one.
  - Find a memento your child can carry around that reminds them of the loved one.
  - Create a memory box to store special keepsakes.

Warning Signs for Seeking Professional Help for the Grieving Child:

Grieving with a loss can take time. If your child exhibits life-disrupting grief beyond six months, your child may need professional help from a licensed and certified counselor. Some of these signs include:

- Nightmares
- Belief that the world is an unsafe place
- Moodiness
- Difficulty sleeping or eating
- Ongoing behavior problems
- Regression behaviors that they may have exhibited when they were younger, such as clinging or thumb-sucking
- Difficulty sleeping
- Detaching or withdrawing from others
- Inability or refusal to go to school, learn or play with friends, and
- Thoughts of hurting themselves or others

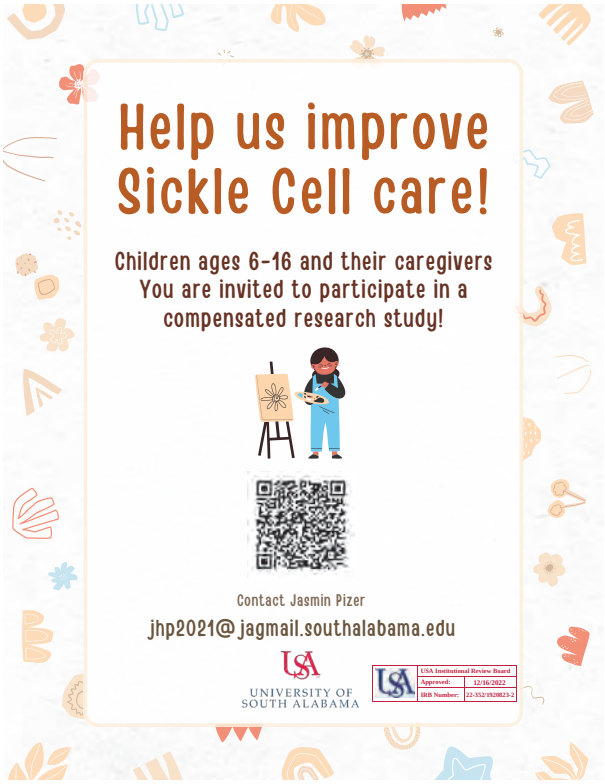


Book Recommendations

- "Samantha Jane's Missing Smile: A Story About Coping With the Loss of a Parent," by Donna Pincus, for ages 5+
- "Everett Anderson's Goodbye," by Lucille Clifton, for ages 5-8, about a father's death
- "Good Answers to Tough Questions About Death," by Joy Berry, for ages 6-12
- "How Angels are Made," by Bryson Thompson Jr. for ages 4 +
- "Help Me Say Goodbye: Activities for Helping Kids Cope When a Special Person Dies," by Janis Silverman, for ages 8+
- "The Invisible String," by Patrice Karst, for ages 3-7
- "When Dinosaurs Die: A Guide to Understanding Death (Dino Tales: Life Guides for Families)," by Laurie Kransy Brown and Marc Brown, for ages 3-8
- "The Next Place," by Warren Hanson, for ages 5 and older
- "Duck, Death and the Tulip," by Wolf Erlbruch, for ages 7-9
- "The Fall of Freddie the Leaf: A Story of Life for All Ages," by Leo Buscaglia, for ages 4-10
- "Maybe Dying is like Becoming a Butterfly," by Pimm van Hest and Lisa Brandenburg, for ages 5-10

Useful Websites:

- courageousparentsnetwork.org
- sesamestreetincommunities.org/topics/grief
- emilyedlynnphd.com/grief-resources
- anxietycoach.mayoclinic.org/family-stress
- dougy.org
- compassionatefriends.org
- genesislegacy.org/resources
- centerforloss.com



Alabama Governor Issues Commendation Recognizing Haynes' Service to USA Health

Alabama Gov. Kay Ivey recently issued a commendation for the late Johnson Haynes, Jr., M.D., that honors his life and dedication to the field of medicine.

Signed on February 22, the commendation notes how he began a career as an African-American trailblazer.

"He joined the USA faculty in 1984 as the first African-American clinical and basic sciences faculty member where he served as a devoted mentor to countless students and a tireless advocate for more opportunities in medicine for students from disadvantaged communities," it reads.

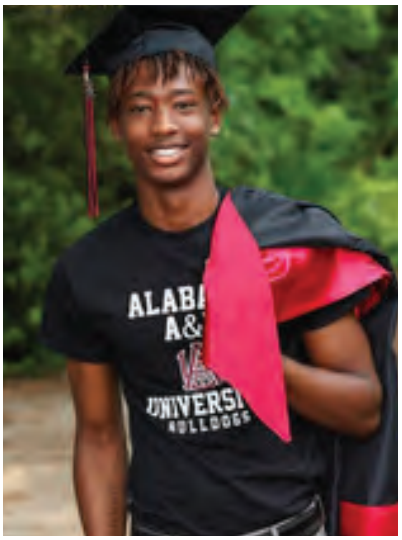
Throughout his career, Haynes was a champion for diversity and representation in healthcare and medical education, and a steadfast mentor to countless medical students and residents.

Much of his career was devoted to the university's Comprehensive Sickle Cell Center, which now bears his name.

The commendation also recognizes his distinguished reputation for expertise in treating sickle cell disease, as well as his devotion to his faith and community.

Pediatric to Adult Care Transition (PACT) Program Participant Spotlight: *Tyler Mason*

T'Shemika Perryman, R.N., PACT Coordinator, and Tyler Mason



The Pediatric to Adult Care Transition Program (PACT) started in 2012 to bridge the gap between the pediatric and adult healthcare systems for sickle cell disease (SCD) participants between the ages of 13 and 21. The goal of PACT is to not only educate participants on their disease process, but also to encourage them to obtain a higher education if that is their goal. In recent years, we have had several participants successfully graduate high school and are currently attending college. The PACT program also has other participants who are planning to attend college to further their education. They are embracing themselves holistically and showing others that they are not defined by their chronic illness. In this article, we will highlight one of our participants, Tyler Mason. As an active participant of the PACT program since the age of 13, Tyler has recently made the successful transition into the adult healthcare system. This is an insight into his personal journey in his own words.

"Hello, I am Tyler Mason. I am a graduating senior from Mobile, Alabama, where I attend Saraland High School. Throughout my lifetime, I have dealt with sickle cell anemia. Although sickle cell disease is difficult to live with, I have not let it define me. In my experience, I have been able to participate in sports and many other activities that I was told would never happen. Even though I had these opportunities, I know that most people dealing with sickle cell disease are not able to do so. However, I encourage everyone to strive for greatness in any passion they have for something despite dealing with sickle cell disease or anything they feel does not represent them. Through my time in high school, I realized sports were not my future; but I set goals to excel in my education and became a scholar. I took honors courses, participated in several clubs, and found my passion for engineering. Growing up, I always loved electronics and wondered how they functioned. In high school, I discovered that I could work with electronics and learned how they function by studying engineering. I decided to participate in engineering classes and programs, which increased my interest in engineering. This ultimately led to my decision to become an electrical engineer. Now, as a graduating senior, I plan to attend an illustrious Historical Black College, Alabama A&M University, to pursue my degree. During my time at Alabama A&M, I plan to get involved on campus and obtain internships to one day achieve my goal of becoming a successful engineer."

Tyler is the first of many young adults who the Johnson Haynes, Jr., M.D. Comprehensive Sickle Cell Center (JHJCSCC) plans to highlight on their successful journey through their education and career while living with SCD. The JHJCSCC hopes Tyler's story like many others inspires the up-and-coming adolescents and young adults with SCD and participants of the PACT program to believe and achieve whatever their goals may be in life. Additionally, the JHJCSCC hopes Tyler's story will be an inspiration for others in that they will not allow SCD to define them.

The JHJCSCC is looking forward to Tyler's follow-up story describing his college journey and life as an electrical engineer.

Congratulations, Tyler Mason!

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

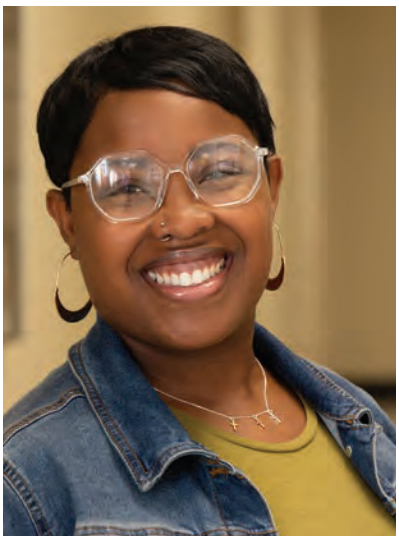
Welcomes New Healthcare Provider, Collaborating Physician

As the center continues the legacy of Dr. Haynes, please join us in welcoming Antwan Hogue, M.D., as the adult sickle cell disease healthcare provider and collaborating physician.

Hogue is a native of Mobile, Alabama, and a graduate of the Frederick P. Whiddon College of Medicine at the University of South Alabama. He trained in internal medicine at the University of South Carolina Palmetto Health Richland/Dorn Veteran Administration Hospital, where he served as chief resident. Since 2015, Hogue has practiced as a hospitalist at USA Health, caring for hospitalized and critically ill patients including those with sickle cell disease. He is currently an assistant professor of internal medicine at the Whiddon College of Medicine.

Hogue is a member of the Alpha Omega Alpha medical honor society, a Gold Humanism Award recipient, and recently recognized as a member of Mobile Bay Magazine's 2023 Class of 40 Under 40. He is married to Ashley Williams, M.D., and they have three beautiful children (Amarii, Ava, and Atlas).

Hogue is very excited about his new role as a sickle cell provider for patients in the community.



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

Welcomes Newest Member, Ariel Jackson

Ariel Jackson, a native of Mobile, Alabama, graduated from John L. LeFlore Magnet High School in 2009. Jackson also attended Virginia College of Mobile, Alabama, and graduated in 2018 with her associate's degree in business. In 2019, Jackson was hired as a patient care preservice associate at the Strada Patient Care Center in neurology, OB/GYN, and family medicine departments. Her duties included assisting patients with scheduling and routing patient calls to other departments efficiently. In 2022, Jackson was promoted to care access associate where she served as a front desk associate for family medicine, where her duties included registration and discharge activities, scheduling appointments, providing initial patient triage, verifying registration information as necessary, collecting payments, and providing excellent customer service. She joined the Johnson Haynes Jr., M.D., Comprehensive Sickle Cell Center's team in November 2022. As the center's executive secretary, she will work alongside Interim Director Ardie Pack-Mabien, Ph.D., FNP-BC, Antwan Hogue, M.D., Jessica King, FNP-BC, and T'Shemika Perryman, R.N. Jackson can be reached at 251-470-5893 or arieljackson@health.southalabama.edu.