ADULT SICKLE CELL CLINICAL PROGRAM

ANNUAL REPORT

2022/2023

UAMS

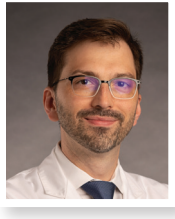
Institute for Digital Health & Innovation

Table of Contents

This annual report was produced by Creative Services and the Office of Communications & Marketing, University of Arkansas for Medical Sciences.

Writing: Benjamin Waldrum | Graphic Design: Amber Fiser, Joe Schaffner
Photography: Bryan Clifton & Benjamin Waldrum

The **University of Arkansas for Medical Sciences (UAMS) Division of Hematology and Oncology in the Department of Internal Medicine** has partnered with the **Institute for Digital Health & Innovation (IDHI)** to create a statewide system of support for patients with sickle cell disease (SCD), and for the physicians who care for them. As UAMS improves and standardizes the treatment of patients with sickle cell disease through the **Adult Sickle Cell Clinical Program,** patients throughout the state with SCD will experience an improved quality of life.



Joseph Sanford, M.D.
IDHI, Director

Rosalyn Perkins, MNSc, WHNP-BC
IDHI, APRN Coordinator, High-Risk Pregnancy Program Director

Rebecca Camp, MNSc., APRN
UAMS Adult Sickle Cell Program

FROM THE DIRECTOR

In 2014, the UAMS Adult Sickle Cell Clinical Program was established to provide optimal care for sickle cell disease patients in Arkansas. This is the only program in the state that caters specifically to adult sickle cell patients. Our team collaborates with primary care physicians, Arkansas Children's, and other specialists across the state to provide personalized treatment plans and resources for our patients. The program also conducts community education and outreach through annual symposiums, radio talks, and other mediums.

At Arkansas Children's, we established the Sickle Cell Disease Program to offer specialized care to our children and communities. As they transition into adulthood, our program continues to provide comprehensive care to enhance our patient's quality of life and increase longevity.

Our multidisciplinary team, which includes an M.D., APRN, RN, clinical social worker, and pharmacist, offers comprehensive care to adult sickle cell patients. We also have the support of pain management specialists from palliative medicine and interventional pain doctors for patients with complex pain issues. Other specialties, such as orthopaedics, physical therapy, cardiology, pulmonology, neurology, etc., also support our team in improving patient outcomes. We have been working hard to streamline the algorithm for treating pain crises in the Emergency Department by developing individualized pain plans for our clinic patients.

Before the establishment of our program, adults with sickle cell disease in Arkansas had limited access to specialized care. We have made significant progress in managing pain and providing access to the latest evidence-based therapies, including stem cell transplants. However, there is still a lot of work to be done, particularly in terms of making gene therapy available to our patients once it is FDA-approved. Our program is participating in the Annual Sickle Cell Disease Workshop, which aims to help programs streamline their operations, collaborate with other sickle cell centers, and expand research abilities.

Overall, we are positive about the direction in which the program is heading, and we are committed to providing evidence-based management to sickle cell patients in our state.

Thank you!

Sunny R.K. Singh, M.D.
Director, UAMS Adult Sickle Cell Clinical Program

PATIENT STORY: CYNCERE TIDWELL

After years of learning how to handle pain crises when they come and developing a routine for care, Cyncere Tidwell says sickle cell disease is just another part of her life.

"Other than the pain crises, sickle cell doesn't bother me," she said. "I've been dealing with it for so long that it's nothing new now. I'm used to it. I don't even tell people I have it unless it comes up in conversation. I don't want to be looked at differently or treated differently."

Tidwell, 22, of Hot Springs, has hemoglobin SC disease, which is a type of sickle cell disease. Symptoms include anemia, where the body doesn't make enough red blood cells, and episodes of fatigue and extreme pain. The severity of the symptoms can vary from person to person.

Thankfully, there have been no serious pain crises for Tidwell since last summer, but she still deals with smaller ones at home, which she controls with pain medication and ibuprofen. She's developed an internal sense of knowing when the pain is bad enough to go to the hospital.

"If it comes every single day, like for three days in a row, then obviously something's wrong," Tidwell said. "I need more [relief] than what I'm getting. If my pain meds I have at home aren't helping then I know I need to go. I'd say that's only once a year."

Tidwell's mother, LaTrice Collins, and her grandmother, Kimberly Huff, both live in Hot Springs and have helped with her care since she was a little girl.

Collins said they use a common 1-10 scale to evaluate her daughter's pain. "If it gets to be eight or above, we know it's pretty much time [to go to the hospital]."

Pain crises were more common when Tidwell was growing up, but both she and her mother said they didn't let it affect her life.

"It didn't prevent me from doing anything, not really," Tidwell said.

"We didn't use it as a crutch," Collins said. "Even if she was in pain, we let her go out and do whatever she wanted to do. We wanted her to be a normal kid. We didn't let sickle cell stop her."

Tidwell transitioned to the UAMS Adult Sickle Cell Clinical Program about a year ago, when she turned 21 and aged out of Arkansas Children's pediatric sickle cell program. She comes to UAMS for checkups every three months.

"They do my blood levels and make sure I'm caught up on my meds, ask me if I've had a crisis," Tidwell said. "Just kind of a check-in." She hasn't needed any blood transfusions as an adult but had "plenty" during her time at Children's.

Tidwell thanked the sickle cell team for her care at UAMS, particularly nurses Rebecca Camp, APRN, and Stella Bowers, RN.

"I love her," Tidwell said of Camp. "But we love Stella too," her mother chimed in. "Yes, I love her too, but Rebecca is my favorite," Tidwell said. "She's so sweet."

Both Tidwell and Collins agreed that stigma is an issue when treating sickle cell patients. During a pain crisis, sickle cell disease patients often seek immediate treatment for their pain in hospital emergency

departments, where they are seen by physicians or resident physicians who have little experience treating patients with sickle cell disease.

"I just wish people would take it more seriously," Tidwell said. "Just because you can't physically see it on a person doesn't mean anything. I work in a hospital, so I've seen other people speak about people with sickle cell. They don't take it seriously."

Collins mentioned the fact that the predominant number of sickle cell patients are African American. "That's another reason it's not taken seriously, I feel like," Tidwell said. Racial bias, including seeing sickle cell patients as drug-seeking, are common barriers to care.

Tidwell stays grounded by focusing on her family and her hobbies. She regularly visits her two brothers, who live in Little Rock, and loves spending time with her niece and nephew. When she's not spending time with her family she enjoys TV, shopping and movies. "I'm a real movie head," she said. "Rom-coms are my favorite."

She also spends time thinking about what's next. A registered nurse, Tidwell works night shifts in labor and delivery at National Park Medical Center in Hot Springs.

"I want to become a traveling nurse — that's my goal," she said. "I would still want to be in labor and delivery, for sure. When the baby comes out, that's the best part."

Tidwell said she knows she wants a future outside of Arkansas. Although the possibilities are endless, she's thinking about her favorite destinations, including New York and Hawaii. Seattle is high on her list because she loves the rain.

"I want to see where I'm going to end up," she said.

Cyncere Tidwell and her mother, LaTrice Collins

TRANSITION PROJECT

For sickle cell disease (SCD) patients, the transition from pediatric to adult care is often a risky time period. During this time, SCD patients often experience a fragmentation in their health care providers and, in turn, their clinical care. Pediatric SCD patients have the option to receive sickle cell management at Arkansas Children's until age 21. However, pediatric SCD patients may begin transitioning care to the UAMS Adult Sickle Cell Clinical Program at age 18. The clinical transition from pediatric to adult care begins years in advance and these age ranges provide SCD patients with individualized plans to ensure more comprehensive care. A key effort during this period is providing a social worker in a dually embedded role at the Children's Pediatric Sickle Cell Clinic and the UAMS Adult Sickle Cell Clinical Program in order to develop relationships with patients and assist them in successfully transitioning their care to an adult health care provider.

The UAMS social workers and the pediatric team have implemented an educational program to help patients prepare for transition. Biannually, patients are provided written and verbal education on various topics, including psychosocial aspects, of their disease. The program ensures every patient receives education on all aspects of their disease and is prepared to transition. In the dual role, the UAMS social worker assists patients with establishing an adult primary care provider in their community (if/when appropriate), as well as their initial appointment at the UAMS Adult Sickle Cell Clinical Program office. Additionally, the clinic team meets with the pediatric sickle cell team at Children's on a biannual basis to review patients who will transition within the next six months. These meetings ensure continuity of care for patients and help strengthen the collaboration between the two clinics.

- **33 patients** have transitioned their care from Children's to UAMS during fiscal year 2023.
- **65 patients** at Arkansas Children's are age 16 or older that can transition at the age of 21.

ADULT SICKLE CELL MULTIDISCIPLINARY CLINIC

The UAMS Adult Sickle Cell Clinical Program uses an interdisciplinary approach to manage adult patients with sickle cell disease. The clinic provides services to patients across Arkansas.

Frequency of clinic visits vary based on each patient's disease severity. Visits can range from monthly to annually or more frequent as indicated. Comprehensive care is tailored to meet the individual needs of each patient. In order to ensure holistic management, the program maintains communication regarding sickle cell management with each patient's primary care provider.

The program's interdisciplinary clinic includes a team of hematologists, physicians that specialize in blood disorders and diseases.

A nurse practitioner works in collaboration with the team to deliver and facilitate holistic care through assessment, treatment plan development, maintenance and follow-up.

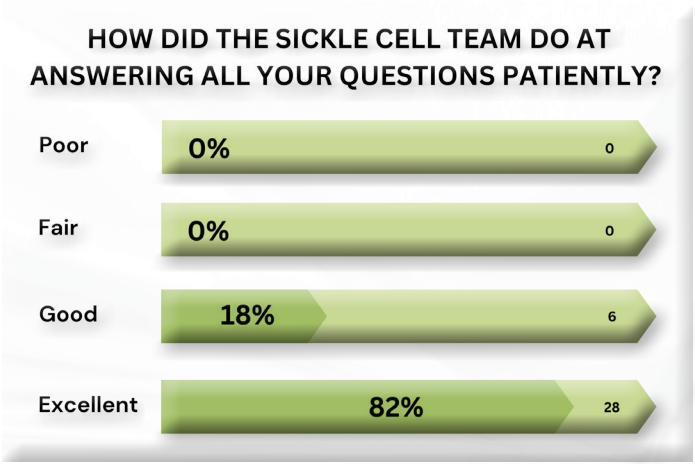
A licensed clinical social worker assists patients and their families with social and emotional support, health-related expenses for the underinsured or uninsured, transportation costs and employment options. Additionally, they work with patients, families and staff to promote successful transition from pediatric care at Arkansas Children's into the adult clinical setting.

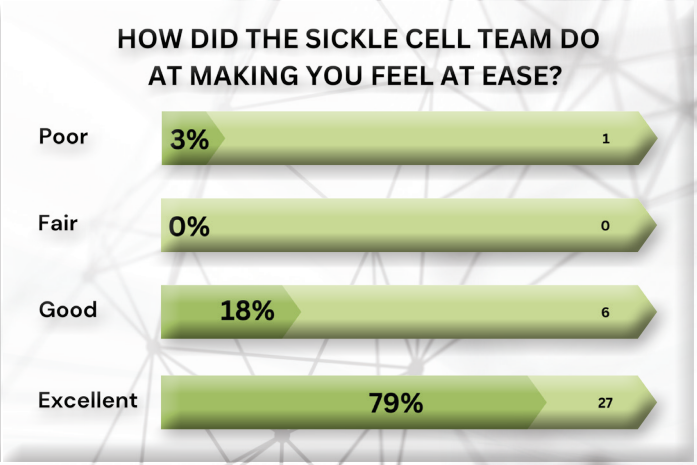
A registered nurse provides care to patients in the outpatient setting and is the liaison between the call center staff, patients and the sickle cell team. They also serve as the community outreach coordinator, helping foster and maintain relationships between the clinical staff, community and countless health care providers around Arkansas.

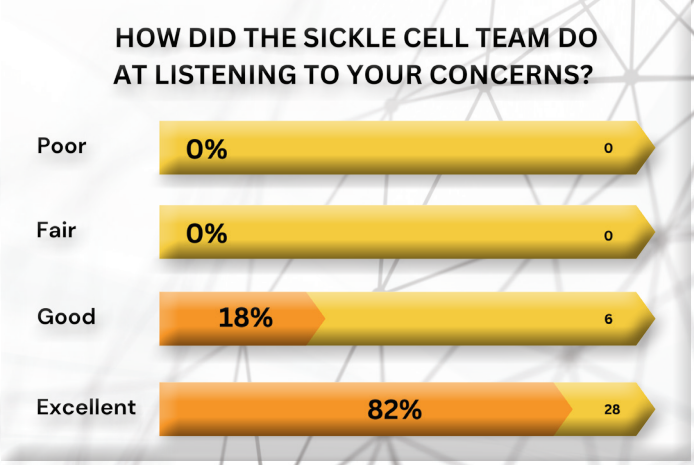
A pharmacist provides medication management through comprehensive reconciliation and counseling, while also assessing medication efficacy.

In addition to these core team members, the program coordinates with health care professionals throughout UAMS to ensure our patients receive the very best care and treatments available.

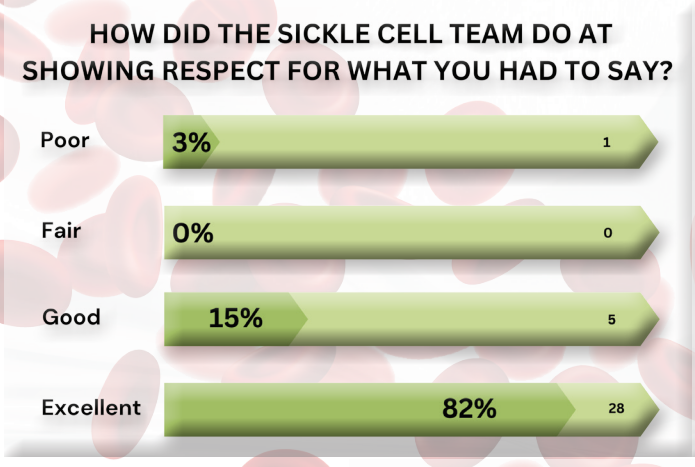
PATIENT SATISFACTION SURVEYS

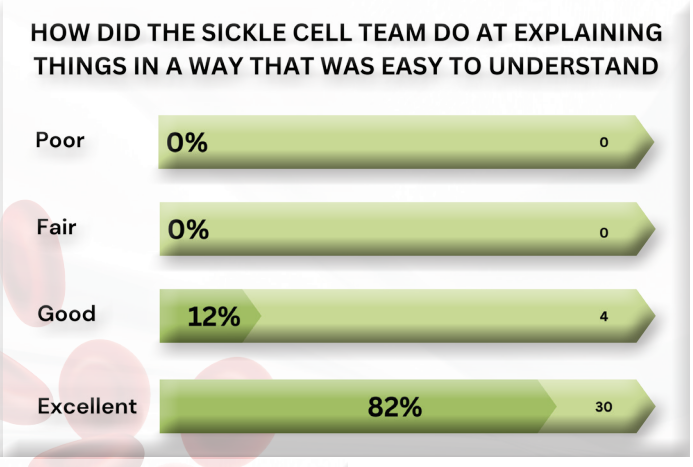


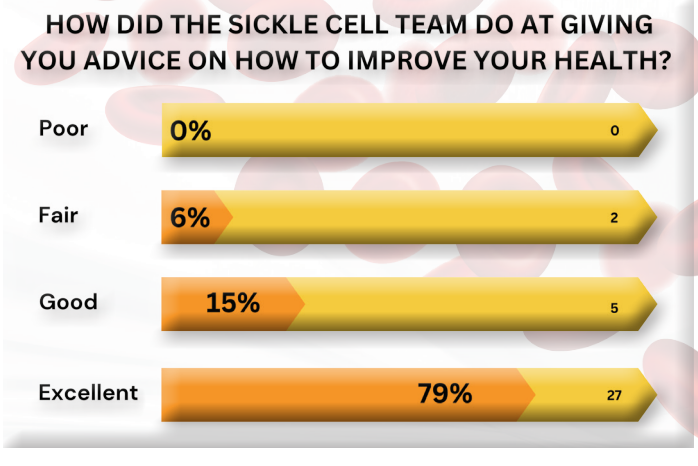




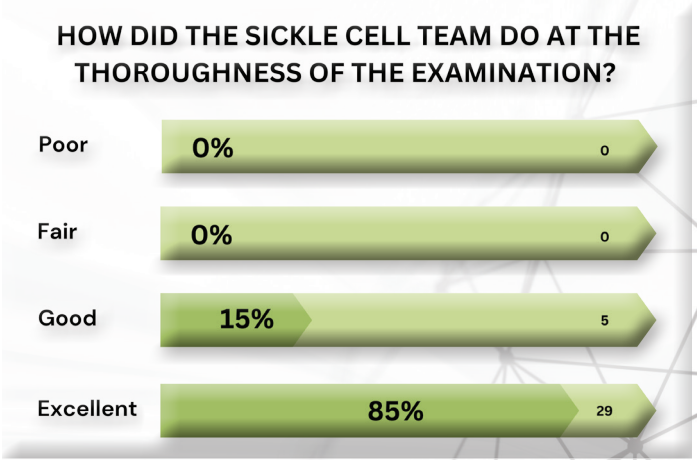
PATIENT SATISFACTION SURVEYS

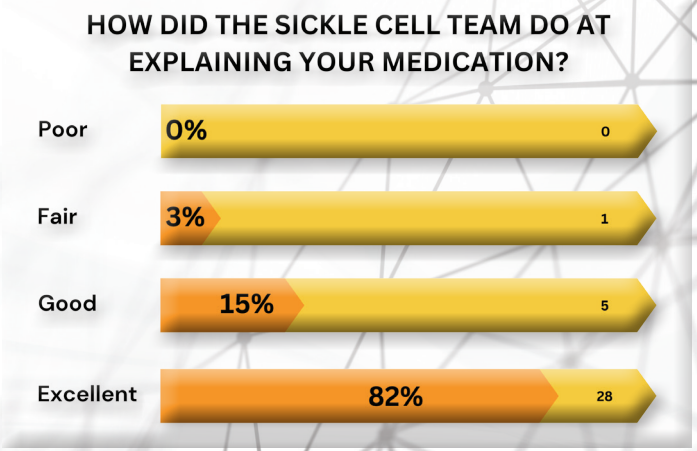




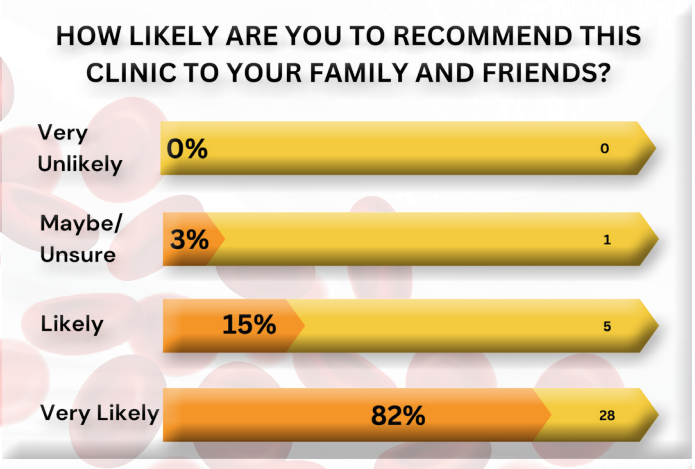


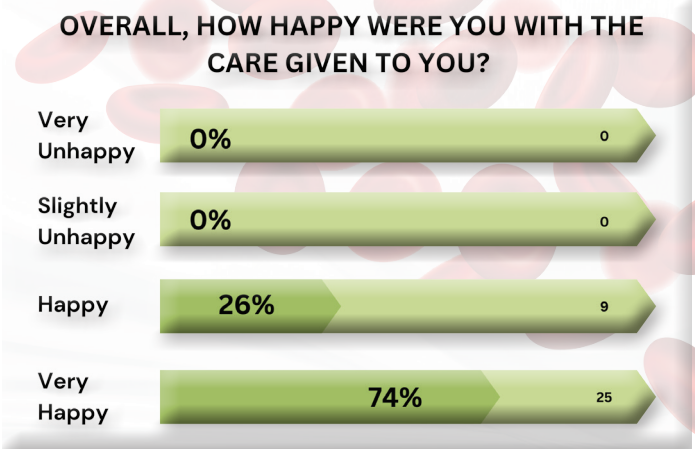
PATIENT SATISFACTION SURVEYS





PATIENT SATISFACTION SURVEYS





CALL CENTER

Sickle cell patients can access the Call Center 24 hours a day, seven days a week. The Call Center is managed by the Institute for Digital Health & Innovation.

Patients can call in with immediate problems, which are triaged by a registered nurse. The triage nurse may advise the patient to go to the Emergency Department for immediate care, schedule a clinic appointment, come in for an outpatient infusion treatment or provide assistance with self-care management at home. Giving the patients direct access to a triage nurse familiar with sickle cell disease, as well as a dedicated UAMS Adult Sickle Cell Clinical Program team providing secondary-level triage, helps patients to determine their next step in treatment.

The call center functions as a resource to patients, physicians and providers, and the community. It is accessible for Arkansas residents, those residing outside of the state, as well as internationally. If physicians and providers have questions concerning patient care or would like to refer a patient to the program, the call center may assist them. The Call Center provides an important component to the program and helps the program to reach the goal of becoming a statewide resource to patients, providers and the community in the state of Arkansas and beyond.

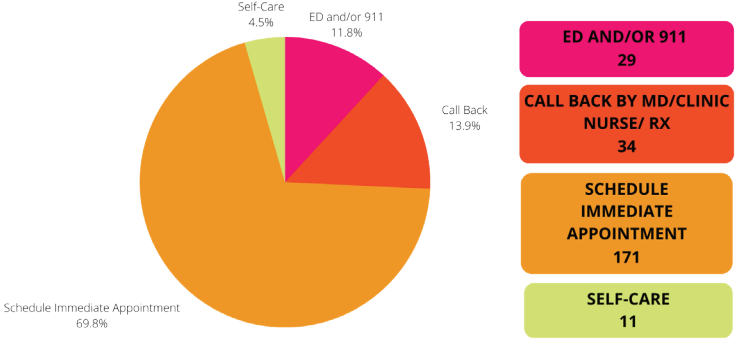
Assisting patients and providers is a major part of the Call Center, but the center also assists the general public.

Digital Health Support

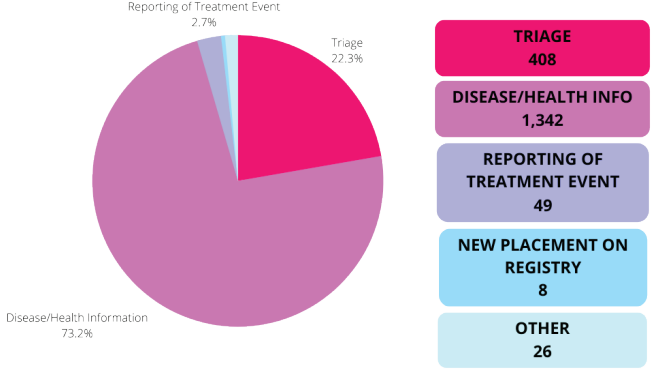
24/7
Call Center with Sickle Cell Hotline

Staffed by experienced RNs who can offer:

- Education concerning acute and chronic health problems related to sickle cell disease
- Doc to doc consults supporting primary care, the Emergency Department (ED), and other providers caring for sickle cell patients across the state
- Telephone triage for patients with immediate health concerns
  - Emotional support
  - Assistance with medication refills
  - Home care instructions to lessen symptoms
  - Secondary-level triage (through the Call Center) before sending patients to ED, giving alternatives to ED visit when appropriate



Call Center Triage Outcomes



Caller Request

EDUCATION AND OUTREACH

SICKLE CELL FALL SYMPOSIUM

Although barriers to care still exist for patients with sickle cell disease, there is hope. Speakers at the UAMS Adult Sickle Cell Clinical Program's second symposium of the year, held during Sickle Cell Awareness Month in September, highlighted successes and challenges in treatment as they looked to the future.

"Sickle cell disease has been with us for a long time, and will still be with us for the foreseeable future," said UAMS Chancellor and UAMS Health CEO Cam Patterson, M.D., MBA, in his opening remarks. "We're making progress in our fight, but there's so much more than we can do. We're proud that UAMS is home to the state's only adult sickle cell treatment program. Early treatment for sickle cell disease remains critical."

Sickle cell disease is a group of inherited red blood cell disorders. Healthy red blood cells are round and travel through small blood vessels to carry oxygen throughout the body. With sickle cell disease, the red blood cells become hard and sticky and result in a C-shape or "sickle."

When sickle cells travel to small blood vessels, they get trapped and block blood flow to the area. This results in pain and may lead to other problems such as infection, acute chest syndrome and stroke. During a pain crisis, sickle cell disease patients often seek immediate treatment for their pain in hospital emergency departments, where physicians or resident physicians who have little experience treating patients with sickle cell disease treat them.

There are approximately 100,000 Americans affected by sickle cell disease, according to the Centers for Disease Control and Prevention (CDC). Sixty percent of those are adults. There are more than 1,000 Arkansans with sickle cell disease, with roughly 20 new cases detected each year.

From left to right: Lametra Scott, Pharm.D., Joseph Sanford, M.D., and Sunny Singh, M.D.

The symposium featured the program's new director, Sunny R.K. Singh, M.D., as well as keynote speaker Lametra Scott, Pharm.D., a nationally known expert on sickle cell disease.

Singh, who joined UAMS in September, is the new director of the UAMS Adult Sickle Cell Clinical Program. Fellowship trained in hematology and

oncology at Henry Ford Hospital in Detroit and at UAMS, Singh has expertise in treating various cancers and blood disorders. He was chief resident at John H. Stroger Jr. Hospital of Cook County in Chicago. He received his medical degree from King George's Medical University in India.

At the podium, Singh reviewed the history of sickle cell disease, including recent advances in the treatment of patients. Modern treatment of sickle cell, he said, should address the patient's physical, mental and emotional needs, and involve hematologists, primary care providers, nurses, psychologists, physical therapists and social workers, among others.

"Sickle cell is a multidimensional and multisystemic disease," Singh said. "It can affect literally every part of the body, and that is why we need a multidisciplinary approach to treating this disease. Patients need social support and an integrative health approach, which is what we offer at our adult sickle cell program here at UAMS."

Singh said that treatment of sickle cell has come a long way in the past 50 years. He cited studies from the CDC that note life expectancy of sickle cell patients has roughly doubled in that time, with child mortality rates decreasing by 158%.

Barriers to better care still exist, Singh said, including the cost of treatment, lack of training among health care professionals who dismiss sickle cell patients as drug-seekers and the distance many patients must travel for care.

Scott is founder and executive director of the Breaking the Sickle Cell Cycle Foundation. Her son, Rickey, has sickle cell anemia type SS. In her keynote address, Scott advocated strongly for better care, citing data to dispel stereotypes about the disease.

Sickle cell disease affects millions of people throughout the world, particularly among those of sub-Saharan African descent, Scott said, but also other areas of the globe including South America, the Caribbean, Saudi Arabia, India and the Mediterranean. Historically, she said, sickle cell disease developed in areas with outbreaks of malaria, a disease caused by a parasite that attacks red blood cells.

"Sickle cell disease is not tied to an ethnicity," Scott said. "It is a blood disease, not a Black disease. Out of all the people that you know, a number of them may be sickle cell trait carriers — and the scary part is that many of those people don't even know it. That is what continues to perpetuate the cycle of sickle cell disease."

Scott said that the social determinants of health, such as a person's living and working conditions, is important to understanding gaps in care for sickle cell disease. The same level of care that has enabled better detection of sickle cell in newborns should also extend to those patients as they age into adulthood, she said.

Racial bias is another roadblock to effective care, Scott said. It comes from a variety of sources, she said, including stigma and stereotypes, longer waits in emergency departments, lack of education among providers, lack of insurance coverage and the high cost of medicines. More help is needed: more

EDUCATION AND OUTREACH

providers, more research, and better access and care as patients age.

"The very system that is put in place to provide health care for patients is actually set up to fail patients, all because of the racial biases that come into play when treating sickle cell patients and the lack of education surrounding treatment," Scott said. "Although we may have new medications and treatments available, if we have these barriers that block patients from getting them, how useful are these new therapies?"

Approximately 40 people attended the symposium virtually or in person. It closed with an opportunity for both speakers to take questions directly from the audience.

The UAMS Adult Sickle Cell Clinical Program launched in 2014. Since then, the program has helped treat hundreds of patients and families. It collaborates with the pediatric Sickle Cell Disease Program at Arkansas Children's and often receives patients when they age out of the program. Last year, UAMS transferred four patients from Children's, Camp said. Overall, the program treats more than 250 active patients across the state.

From left to right: Joseph Sanford, M.D., Stanley Ellis, Ed.D., and Chancellor Cam Patterson, M.D.

SICKLE CELL TEAM ATTENDS WORKSHOP IN D.C.

Team members from the UAMS Adult Sickle Cell Clinical Program were on hand May 8-11 to attend a sickle cell disease workshop in Washington, D.C.

Hosted by the American Society of Hematology (ASH), the goal of the workshop was to train health care professionals to establish a clinical center focused on the needs of adults living with sickle cell disease. It was the fourth such workshop put on by ASH.

The workshop walked participants through the common components of these centers and shared tips on developing a business plan and advocating to stakeholders, as well as the ins and outs of operations. There was also discussion on how to measure impact and how to improve on the quality of care the centers provide.

Sickle cell team members Sunny Singh, M.D., Stella Bowers, RN, and Rebecca Camp, APRN, were among those awarded a grant by ASH to attend the workshop. Attendees were selected from comprehensive care centers nationwide to share knowledge on how they provide care. The workshops help build a professional network of leaders in adult sickle cell care, with the goal of improving outcomes for sickle cell patients.

From left to right: Rebecca Camp, APRN, Sunny Singh, M.D., and Stella Bowers, RN

The UAMS sickle cell team will be meeting with ASH leaders nearly every month for the next year to build on concepts introduced in the workshop. They will attend a follow-up workshop in May 2024 to reinforce what they have learned and share successes of the UAMS Adult Sickle Cell Clinical Program.

PATIENT STORY: XAVIUS HYMES STORY

Xavius Hymes and members of his family, who have supported him throughout hospital stays like the one pictured.

Sickle cell disease hasn't made life easy for Xavius Hymes, 27, of Pine Bluff, but he hasn't let it keep him from dreaming big. In fact, he uses the disease as fuel to keep going.

"If anything, I feel like sickle cell anemia has made me mentally stronger," Hymes said in a YouTube video. "It's definitely taught me to roll with the punches, and not letting your current situation be your outcome. There's a lot more to you than what you're going through at this moment. Don't let it hold you back from experiencing life."

Hymes was born with sickle cell anemia, sometimes called SS sickle cell because of the two "S" sickle cell genes inherited from each parent. It is the most severe form of the disease. This often means multiple pain crises every year.

For Hymes, weather is the most common trigger.

"Mostly it's drastic weather changes for me," Hymes said. "Let's say it's been 70 degrees for a couple of days, and then it drops to 40 or 30 [degrees] — that could cause me to have a crisis."

That continued as he got older, affecting his ability to attend school and play sports.

"I missed quite a bit of school during the colder seasons," Hymes said. "I got to play sports for a while until I got to 11th grade, and they suggested that I stop because of sickle cell."

Hymes remembers having his first pain crisis when he was 5 years old, the same day as his biological father's funeral. That was when he was a patient in the pediatric sickle cell program at Arkansas Children's. He credits Suzanne Saccente, M.D., a pediatric hematologist/oncologist and associate professor in the Department of Pediatrics, and Angela Mull, RN, with his care.

Since transitioning to the UAMS Adult Sickle Cell Program, Hymes said the main difference is that he now takes a larger role in his own care. He often makes hospital trips himself, but his family helps make sure he's recovering well. Checkups range from every three to six months.

"At this point, they kind of expect you to handle more on your own, to be preventative and stuff, versus when you're a child, and they're a lot more hands-on," Hymes said.

Hymes was grateful to a number of people with the UAMS sickle cell team for his care, including nurses Stella Bowers, RN, and Rebecca Camp, APRN, as well as internal medicine doctors Hasan Rana, M.D., Fatima Khan, M.D., Nazish Malik, M.D., and his primary physician, Toni Middleton, M.D..

Sickle cell is more of a road bump for Hymes, who is determined to keep busy.

Hymes has been enrolled in a post-baccalaureate program through the UAMS College of Medicine that helps students apply to medical school. He also works at UAMS through the Division of Diversity, Equity and Inclusion, assisting with summer health programs. Eventually, he wants to become a physician to help fellow sickle cell patients and many others in need.

However, all of that has been on hold for the past year while Hymes has been receiving additional treatment at Children's Hospital Colorado in Aurora, Colorado. The UAMS sickle cell team keeps up-to-date

on his care there. His plan is to re-enroll at UAMS in the fall.

"I want to continue on and go to med school, and become a physician," Hymes said.

Over the past three years, Hymes has been posting videos on YouTube chronicling his journey as a sickle cell patient. He records his doctors' visits, showing every needle stick and IV. Sometimes he cracks jokes with the nurses while he waits for an infusion. Others show him in a hospital bed in the early morning hours. He dedicated one video to explaining his worst sickle cell crisis, where extreme constipation kept him from eating for five days.

"I wanted to show people they could still have a normal life with a chronic illness," Hymes said in his first video. "They don't have to surrender to that illness. Use it as a motivation, to push yourself to do more, which helped me a lot. Think of it as a motivation instead of a hindrance."

There are still unpredictable, painful days that require hospital visits. Hymes said he only goes to the hospital as a last resort, when he can no longer control his pain at home.

There are also stigmas that many patients contend with. Sickle cell patients are often stigmatized as being drug-seeking, which Hymes said is frustrating.

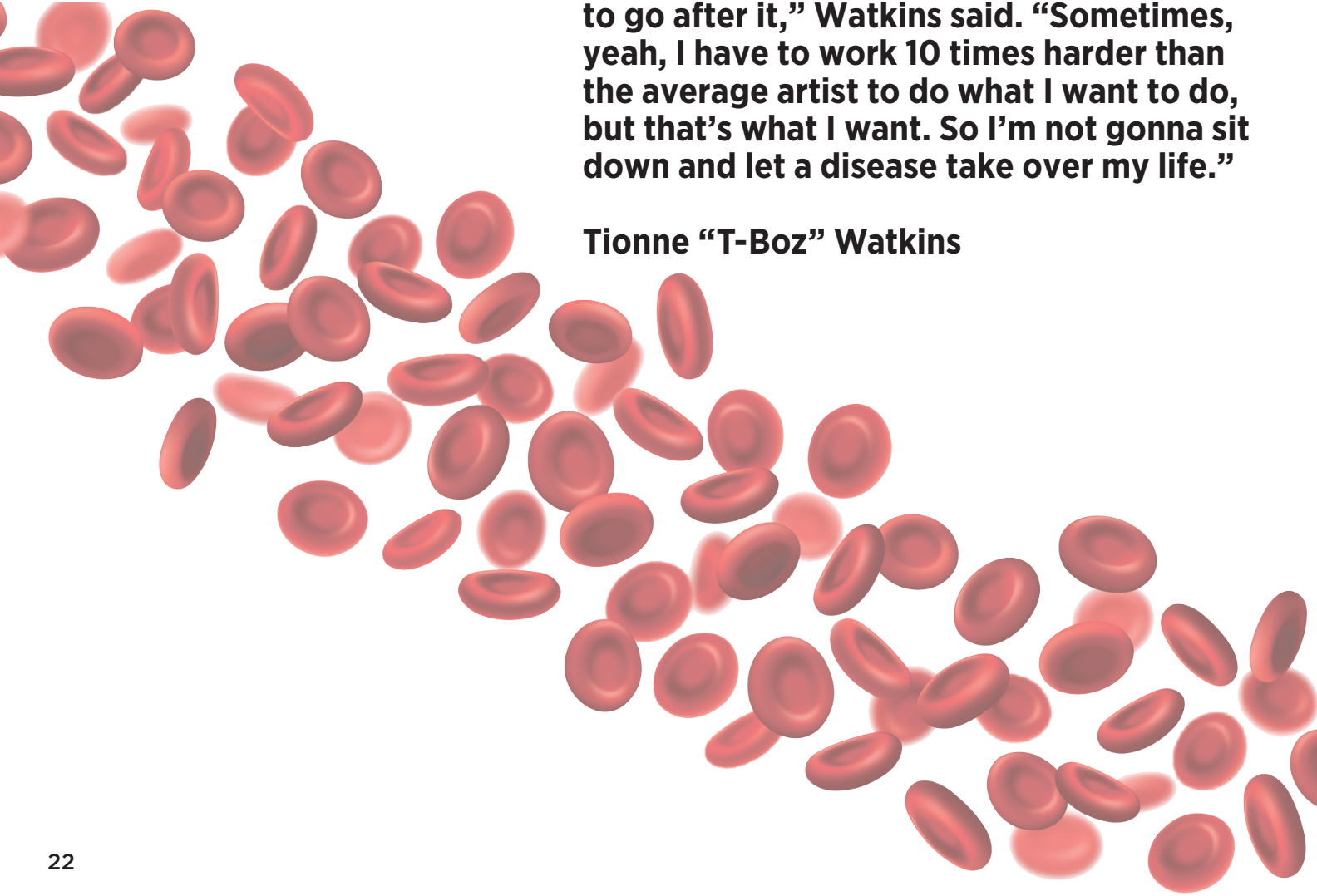
"It's unpredictable; we can't control when we get sick or when we have pain," Hymes said. "So, needing to get pain medicine and fluids — if we didn't have to be there, a lot of us wouldn't be there. Being looked at like, we're just there for pain medicine. Of course we're there for pain medicine, because when you're in pain the only thing you want to be is out of pain."

Hymes said keeping a positive outlook has helped him get through the hard times.

"You feel like you're getting ahead or making forward progress, it seems like those moments are when you have a sickle cell crisis or something that pushes you back," Hymes said. "After stuff like that happens it's important for me to keep a positive mindset so I don't get stuck in a rut."

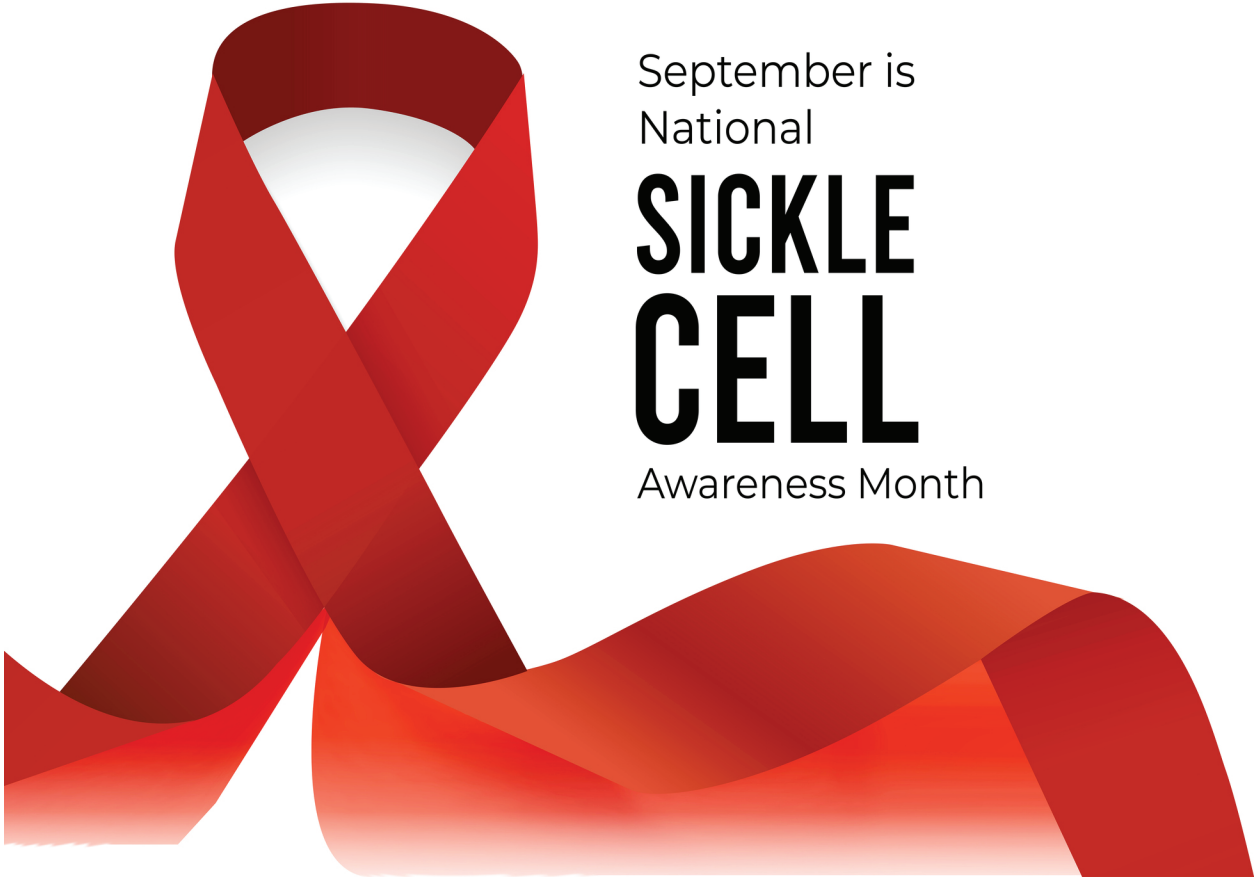
In his free time, Hymes said he enjoys going to zoos and aquariums, which is something he's making the most of during his time in Colorado. Once his treatment there is complete, he's looking ahead to starting medical school and using his knowledge to help others.

"I can't wait to be able to give back and repay the people who've poured into my life: my parents and grandparents, the doctors and nurses — everyone, really," Hymes said. "I'd just like to show how much I appreciate everyone. I'm not sure exactly how, but I look forward to that the most."



“If you want something in life, you have to go after it,” Watkins said. “Sometimes, yeah, I have to work 10 times harder than the average artist to do what I want to do, but that’s what I want. So I’m not gonna sit down and let a disease take over my life.”

Tionne “T-Boz” Watkins


September is
National
SICKLE
CELL
Awareness Month

UAMS

Institute for Digital
Health & Innovation

For patient services call the 24/7 Call Center
at **1-855-Sic-Cell (742-2355)**

For more information visit
sicklecell.uams.edu