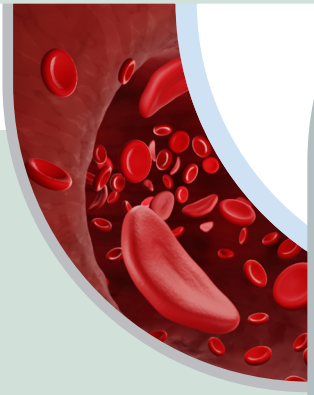

ADULT SICKLE CELL PROGRAM

ANNUAL REPORT

2021/2022

UAMS

Adult Sickle Cell Clinic

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The **University of Arkansas for Medical Sciences 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

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

FROM THE INTERIM DIRECTOR

The UAMS Adult Sickle Cell Clinical Program was launched in 2014 to provide the best possible care for patients with sickle cell disease in Arkansas. This is the state's only program for adult sickle cell patients, and we collaborate with primary care physicians across the entire state, providing resources and individualized treatment plans for patients.

Arkansas Children's established the Sickle Cell Disease Program to give our children and communities the specialty care needed to combat the disease. Our program is able to take the baton as they grow into adults to provide specialized care — all under one umbrella,— ultimately enhancing our patients' quality of life and increasing their longevity.

Ours is the only comprehensive program with the sickle cell care team that is composed of a M.D., APRN, RN, clinical social worker and pharmacist. There is also pain management support from palliative medicine physicians and interventional pain doctors that help co-manage patients with complex pain issues. This team serves the needs of every patient who attends the clinic.

Many of our adult sickle cell patients also suffer from dependence problems related to the treatment of their painful crises. Careful arrangement for patient follow-up, social support and family counseling are all an important component for the care of these patients. Psychopharmacology, mental health visits and complex care to patients with advanced disease are some of the unique care rendered only at this comprehensive clinic to sickle cell patients.

Before the inception of our clinic, many adults with sickle cell disease in Arkansas had limited access to specialized care. Although we have made significant strides in managing pain and updating treatment plans, the next horizon is finding a cure for sickle cell disease, which is most prevalent in minority communities.

There are currently two curative interventions available: gene therapy and bone marrow transplant. Our program collaborates with patients and other health care centers to make these interventions available to this population. In the future, we are hopeful to expand our services to include these treatment options. We look forward to continuing to serve this patient population through evidence-based management.

I am excited to welcome the incoming director, Sunny Singh, M.D., who has special interest in sickle cell disease with vast experience treating sickle cell patients during his residency training. He will take the lead in jump-starting the sickle cell registry, opening new clinical trials and possible collaboration with major sickle cell centers across the nation to integrate care and research and open new horizons.

Cheers,

Muthu Veeraputhiran, M.D., MPH, FACP
Interim Director, UAMS Adult Sickle Cell Program

FROM THE INCOMING DIRECTOR

Prior to coming to UAMS, I attended medical school at King George's Medical University in India, trained in internal medicine at John H. Stroger Jr. Hospital of Cook County, Chicago and stayed on for a year to serve as chief medical resident. Cook County Hospital is an inner-city safety net hospital which takes pride in caring for the underserved, uninsured, socially challenged and diverse patient population of Chicago. The experience there during residency shaped my career goals and aspirations. I was extremely lucky to have some exceptionally dedicated physicians as mentors which got me interested in hematology/oncology. Also, humbling experiences with patients, especially individuals living with sickle cell disease, further strengthened my commitment to take up this area of medicine. I was accepted for a hematology oncology fellowship at Henry Ford Hospital, Detroit where I trained for two years before moving to Little Rock. Henry Ford Hospital has a comprehensive sickle cell program, and this gave me the opportunity to further my fund of knowledge and skills. I then came to UAMS to complete my fellowship and was very excited to be given the opportunity to be a part of the comprehensive sickle cell program here.

These are exciting times in medicine, and especially in the treatment of sickle cell disease. Decades-long research efforts in the field of genomics, proteomics and bioengineering are finally bearing fruit. We are seeing an explosion in novel treatment approaches for hemoglobinopathies, including sickle cell disease. The opportunity to serve as director of the UAMS Adult Sickle Cell Clinical Program gives me the chance to serve patients and families of Arkansas who are living with this challenging disease. I am also eager to be a part of this team that is devoted to bringing the latest and best treatments that science has to offer to our patients.

Our amazing patients and families deserve a dedicated, passionate and professional multidisciplinary team caring for them and the Adult Sickle Cell Clinical Program here at UAMS is structured to deliver the same. I am excited to be part of a team that includes nurses, social workers and pharmacists. Also, I look forward to partnering with colleagues from palliative care, transfusion, interventional pain, psychology/psychiatry, OB/GYN, orthopaedics, physical therapy, cardiology, pulmonology and others with the common objective of improving outcomes of our patients with sickle cell and supporting them from every angle.

My goal over the next few years, in addition to providing compassionate and effective clinical care, is to ramp up research efforts of our department and bring in clinical trials. This will allow our patients to benefit from the most recently developed therapies and will also help us to advance the science of sickle cell disease. We will continue to deepen and expand our collaboration with other institutions with the aim of learning from leaders in the field while also constantly improving care delivery to our patients, in our quest to meet the expectations of excellence of our fellow Arkansans.

Last but not the least, I am grateful to UAMS leadership for trusting me with this immense responsibility. I eagerly look forward to meeting our patients and their families and listening to their stories. The sickle cell team at UAMS is committed to walking and supporting beside our patients and support them in their journey.

Sunny Singh, M.D.
Program Director

Father Fights Sickle Cell's 'War on the Inside' to Spend More Time with Family

By: Karmen Robinson and Benjamin Waldrum

Tyrrence Sanders, 31, wants his children to know they can do anything they put their minds to. And he plans to be there with them, every step of the way.

"Spending time with family is the most important thing to me," he said.

It's a feeling that's deeply embedded in his own experience. Sanders grew up playing multiple sports in his hometown of Waldo, Arkansas. It was something his mother Pamela encouraged.

At some point, she realized something was wrong with his health, and that started a series of hospital and emergency room visits. It was about a two-hour drive to Arkansas Children's from Waldo.

"My mom tried to make sure I lived a normal life because she didn't want me to feel any different from other kids," said Sanders, who grew up playing baseball, football and basketball. "She made sure I stayed hydrated and didn't overdo it.

"I had a normal childhood until it was time to go to the emergency room," he said. "Family members knew what was going on, but not everyone else."

Sanders has 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.

For Sanders, this means many painful episodes each year. He takes a pain pill every day, and another if the pain is intense. He also tries to ease his pain with heating pads and hot showers.

"Living with sickle cell — it's just not a one-day thing. When people look at you, they don't know what's going on," he said. "They just think you're another human being because we look fine on the outside, but it's a war on the inside. I could be fine now, or we could be laughing and talking, and I'm hiding my pain."

Sanders has worked since he was 16, but like many other people with sickle cell, it was difficult for him to maintain employment due to the severity of his pain that forced him to miss work.

Some doctors don't know about sickle cell, and therefore, they don't know how to manage the pain in a safe way. For Sanders, it became a particularly scary experience.

"I had pneumonia in both of my lungs. My doctor couldn't figure out what was going on," he said. Eventually an ambulance drove him to the airport, and he was put on a flight to Little Rock.

"Next thing I know, I'm at UAMS," he said. "That's when I met everyone."

That was three or four years ago, by Sanders' estimate. Today, he lives in Texarkana and makes regular visits to the UAMS Sickle Cell Clinic.

"Before I started coming to the clinic, it was rough," he said. "I was going to the ER three to four times a month and was being admitted to the hospital six to seven times per year. After my first year coming to the clinic, I went to the ER once or twice but wasn't admitted to the hospital all year."

Every eight weeks, Sanders receives apheresis treatments that remove some of his red blood cells and replace them with new ones. It's one way to help treat sickle cell and prevent clotting.

"That allows me to do things I couldn't do before," he said. "I can live my life better and do things with my son and daughter. Do things with my family."

These days, Sanders is focused on his family — fiancée Chelsea, son Trae'vion, 11, and a new addition — baby Madisyn, born in April. His mother Pamela and sisters live nearby, too. Together with his close friends, they've formed a tight support system.

Trae'vion and Madisyn only carry the trait for sickle cell, which is a good thing, Sanders said. And thanks to the treatment he receives at UAMS, he can keep up with their energy.

"Trae'vion wants to play sports, go outside, go fishing," Sanders said. "If I tell him we're going to go fishing, I'm not worried about breaking my promise to him."

As a nurse left the room after tending to Sanders, he said, "I'm glad that I have good nurses like her. It's good that they have this program now, because after you leave Children's [pediatric sickle cell clinic], it's nothing out there besides a PCP who really doesn't know too much about sickle cell. You just tell a doctor what's wrong and what's going on with you, and they just try their best to figure out what to do."

Sanders said he's glad the state has an adult program. He's thankful for the clinic and its staff, especially 'Miss Stella' as he calls Stella Bowers, RN.

"It's tough to deal with sickle cell as a child, because you don't know what's going on with yourself, and you were just hurting," he said. "Now that I'm older, I know what's going on, and what I can do about it. If I have questions or if I'm in pain, they have an answer at the sickle cell clinic. I rate them 100 out of 100."

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 Clinic at age 18. The clinical transition from pediatric to adult care begins years in advance and these age ranges provide SCD patients 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 sickle cell clinic in order to develop relationships with patients and assist them in successfully transitioning their care to an adult health care provider. The UAMS social worker 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 sickle cell clinic. Additionally, the clinic team meets with he Children's 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.

- **7 patients** have transitioned their care from Children's to UAMS during fiscal year 2022.
- **87 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.

UAMS Adult Sickle Cell Clinical Program

Front Row, Left to Right: Lindsey Dayer, Pharm.D., Muthu Veeraputhiran, M.D., MPH, FACP Back Row, Left to Right: Stella Bowers, RN, Sunny Singh, M.D., and Rebecca Camp, APRN

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.

APRN COORDINATOR

Rebecca Camp, MNSc., BSN, APRN, has only been with the UAMS Adult Sickle Cell Clinical Program since February, but she already knows it's right where she wants to be.

A lifelong Arkansan, Camp became a registered nurse in 2010 and obtained her Bachelor's of Science in Nursing from the UAMS College of Nursing that same year. She spent seven years as a medical surgical nurse and received her Masters of Nursing Science degree from UAMS in 2016. For the past six years, she has practiced as an adult primary care APRN, managing chronic health conditions and promoting wellness and preventive care.

Camp handles many responsibilities within the program. She works directly with patients, evaluating lab results, providing education and nutritional information, promoting smoking cessation, assisting with prescription refills and returning calls to the clinic. The adult sickle cell program is contract-funded, and she files monthly reports showing that the program is meeting or exceeding expectations. She also assists with organizing program events and participating in community outreach efforts.

It's a multifaceted job that requires Camp to pivot as the situation demands. She's passionate about promoting education, particularly with smoking cessation.

"Oxygen levels are already challenging to maintain due to sickle cell patients having more sickled red blood cells than healthy ones, and lower oxygen levels can trigger a pain crisis," Camp said. "I talk to everyone who smokes or who is around smoke. Without judgment, I offer assistance and give them information to help them think about quitting. I believe cessation is so important and will improve quality of life."

Camp said she gets the most enjoyment out of helping her patients live better lives.

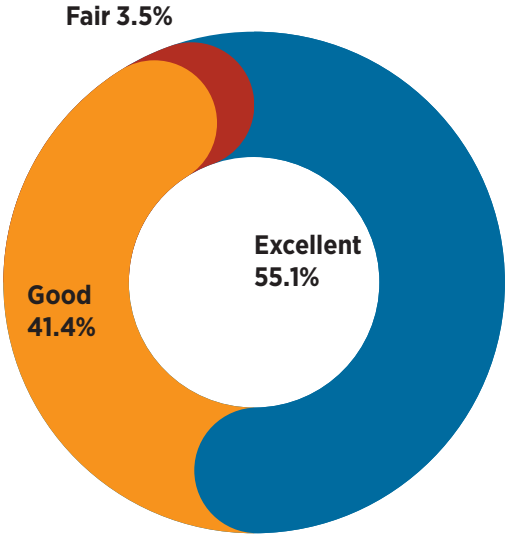
"The most rewarding part of my work is the opportunity to work with an interdisciplinary team to develop a plan of care for our patients," she said. "When the patient starts on a new treatment plan and comes in for follow-up with little to no pain after having one to two ER visits a month — that feels good. I see them getting to work at their job, enjoying their families and having a more active life."

Camp is proactive about finding new avenues for patient education. It's something she takes seriously. With such tasks as assisting with website content, posting QR codes in clinic rooms, mailing postcards and sharing handouts directly with patients, there's plenty to keep up with.

The future of the program is bright, Camp said, and she looks forward to being part of it.

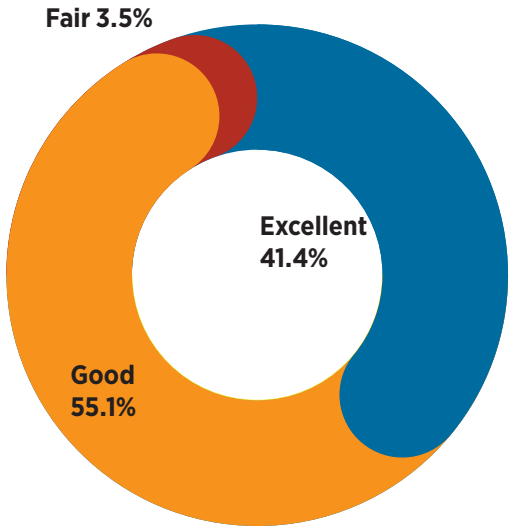
"We have a new director coming on board this summer, and I look forward to having a designated sickle cell physician to collaborate with," she said. "We have on our team a social worker, a RN, an APRN, and physicians working together toward goals that improve outcomes and continuity of care. I feel more empowered and confident in the care our patients receive with the sickle cell interdisciplinary team."

PATIENT SATISFACTION SURVEYS

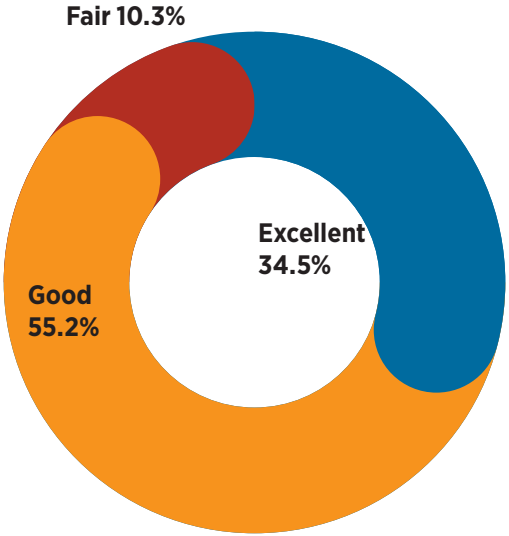


HOW DID THE SICKLE CELL TEAM DO AT
MAKING YOU FEEL AT EASE?

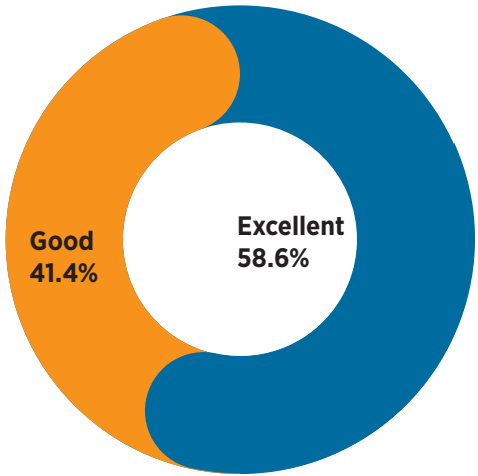
HOW DID THE SICKLE CELL TEAM DO AT
LISTENING TO YOUR CONCERNS?



PATIENT SATISFACTION SURVEYS



HOW DID THE SICKLE CELL TEAM DO AT **ANSWERING ALL YOUR QUESTIONS PATIENTLY?**

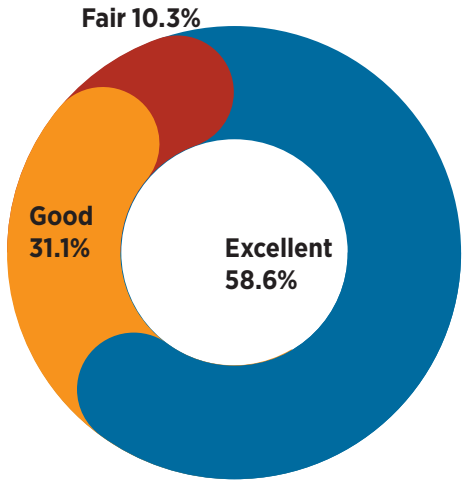


HOW DID THE SICKLE CELL TEAM DO AT **THOROUGHNESS OF THE EXAMINATION?**

PATIENT SATISFACTION SURVEYS

HOW DID THE SICKLE CELL TEAM DO AT **EXPLAINING THINGS IN A WAY THAT WAS EASY TO UNDERSTAND?**

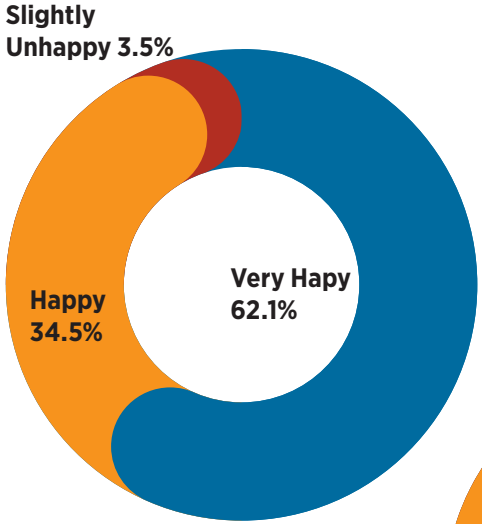
HOW DID THE SICKLE CELL TEAM DO AT **EXPLANATION OF YOUR MEDICATION?**



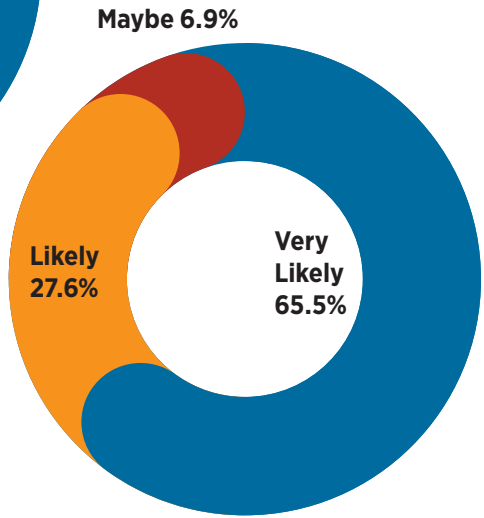
HOW DID THE SICKLE CELL TEAM DO AT **SHOWING RESPECT FOR WHAT YOU HAD TO SAY?**

PATIENT SATISFACTION SURVEYS

HOW DID THE SICKLE CELL TEAM DO AT
GIVING YOU ADVISE ON IMPROVING YOUR HEALTH?



OVERALL, HOW HAPPY WERE YOU WITH THE CARE GIVEN TO YOU? 1=Very Unhappy 2=Slightly Unhappy 3=Happy 4=Very Happy



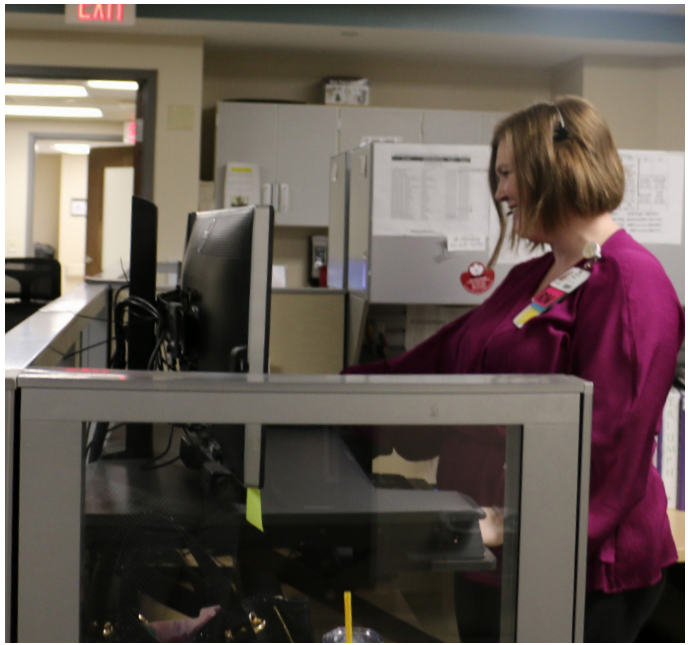
HOW LIKELY ARE YOU TO RECOMMEND THIS CLINIC TO YOUR FAMILY AND FRIENDS?

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 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:

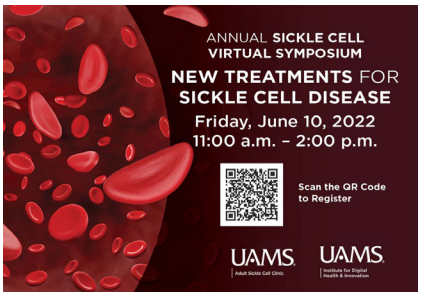
- Education concerning acute and chronic health problems related to sickle cell disease
- Telephone triage for patients with immediate health concerns
  - Emotional support
  - Assistance with medication refills
  - Home care instructions to lessen symptoms
  - Secondary-level triage (through the Call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

- Triage
- Disease/Health Information
- Reporting of Treatment Event for Registry
- M.D. Consult or Transfer
- New Placement on Registry
- Other

- ED and/or 911
- Call back by M.D./clinic nurse/RX
- Schedule Immediate Appointment
  (includes clinic or infusion appointments)
- Self Care

EDUCATION AND OUTREACH

Despite the COVID-19 pandemic, the mission of our program continues to focus on spreading awareness and education on sickle cell disease (SCD). With educational opportunities limited due to the pandemic, we have relied on technology in order to continue spread awareness. Digital health has been beneficial in the clinic and for providing our patients with a platform for education and information. Connecting Across Professions talks are another source of education for providers and health care workers. These opportunities allow our program to educate and make providers aware of what the clinic can offer to them and their patients. Moving forward, we have increased our in-person clinic visits, but are still limiting contact with other areas in the hospital. Our first priority continues to be our patients' safety.




Rebecca Camp, APRN

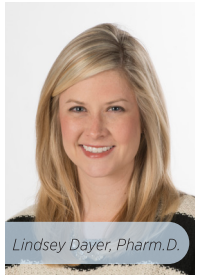

Stella Bowers, RN

This year the annual symposium took place virtually and focused on new treatments for sickle cell patients. Stella Bowers, RN and Rebecca Camp, MNSc., BSN, APRN, presented on the state of sickle cell in Arkansas. Their recommendations were to increase the availability of stem cell transplants, which are the only known cure for sickle cell disease, and increase support for research and clinical trials. There is also a need to increase access through more informed providers, digital health options and education outreach. There were also two presentations on relatively new drug treatments for sickle cell patients: voxelotor, which increases hemoglobin to reduce anemia in patients; and crizanlizumab, FDA-approved in 2019, which inhibits platelet aggregation to help keep red blood cells from clumping together. We are looking forward to continuing our partnership with Future Builders and the Little Rock Black Nurses in September for our upcoming 2022-2023 symposium.

EDUCATION AND OUTREACH

There is a new community-based organization in the sickle cell community: Sickle Cell of Arkansas (SCOAR). Sickle Cell of Arkansas Foundation is a nonprofit organization to help the needs of sickle cell patients and their families in the state of Arkansas. We look forward to finding ways to partner with them to better serve our sickle cell patients in the state.

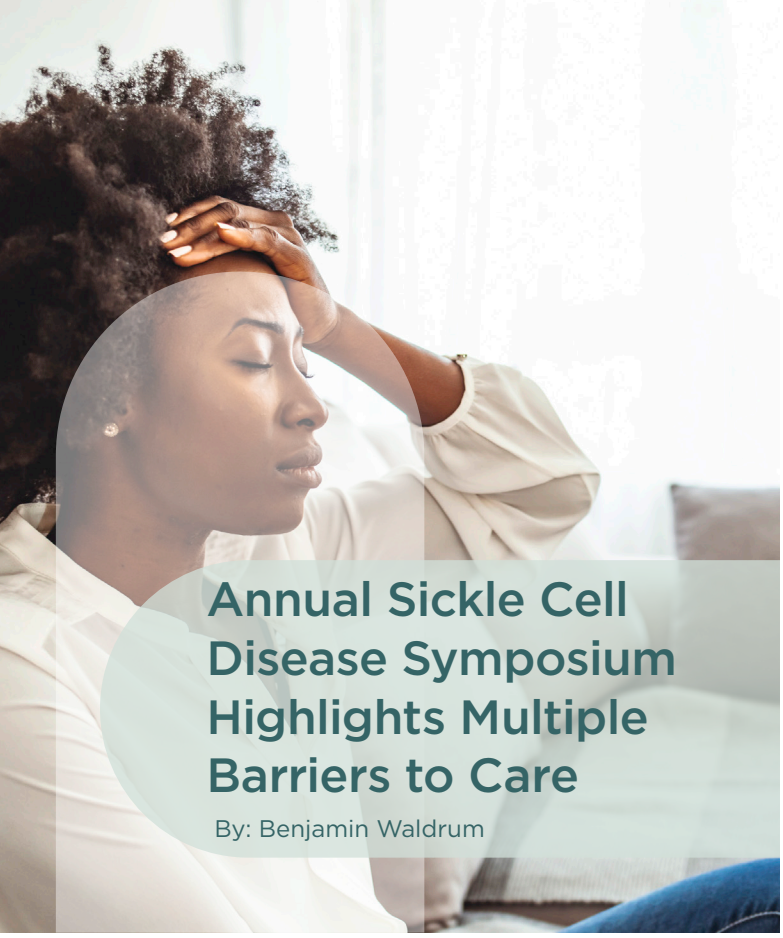
We have resumed community education through visiting health fairs, conferences, schools, churches and other venues to raise awareness of SCD and the UAMS Adult Sickle Cell Clinical Program.


Lindsey Dayer, Pharm.D.

Lindsey Dayer, Pharm.D., the program's pharmacist, presented with Susan Trieu, Pharm.D., director of Enterprise Specialty Clinical Solutions, in October at the Academy of Managed Care Pharmacy Nexus 2021. Their presentation, called Insights into Sickle Cell Disease: Complexities of Care, focused on the scientific advances and optimal management of SCD. Dayer and Trieu discussed the various symptoms that SCD patients present with, and reviewed disease management and multiple drug therapies currently available. They also highlighted the health-related quality of life and economic burden of SCD that patients face. The presentation was broadcast live nationwide from Denver, and reached more than 350 participants either in person or virtually, including many pharmacists and health care professionals.

Dayer, an instructor in the UAMS College of Pharmacy, also presented to her students on sickle cell disease management and pain management.

This year, for the first time, our program participated in the Neighborhoods USA Conference, which had participants from across the country. Education and outreach have been a challenge over the last year, but we are always available via our call center, and education is available via the UAMS patient education site. As we work to safely shift back to community education and outreach, we will continue to raise awareness of SCD.



Annual Sickle Cell Disease Symposium Highlights Multiple Barriers to Care

By: Benjamin Waldrum

Adult sickle cell patients continue to benefit from increased awareness and newly available therapies. However, lack of research funding and access to care, as well as perceived bias from health care professionals, are still impediments to better care.

That was the message from the annual UAMS Sickle Cell Symposium, held virtually June 10. The symposium was streamed live to about 20 participants.

Program coordinators Stella Bowers, RN, and Rebecca Camp, APRN, spoke at length about the state of sickle cell disease in Arkansas.

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

There are approximately 100,000 Americans affected by sickle cell disease, according to the Centers for Disease Control and Prevention. 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.

The overwhelming majority of sickle cell disease patients are Black.

Newborn screenings have helped begin treatment early, but it took many years for them to be put into effect, Camp said. Screenings were developed in 1973 but not used in Arkansas until 1988, and were not universally adopted in the United States until 2006.

"Historically, there have been barriers to care in the sickle cell population," Camp said.

More treatment options have become available, especially in recent years, but clinicians with experience treating sickle cell remain limited, Camp said. Distance to travel is another issue, including in Arkansas, where the only specialty clinics are in Little Rock.

"There are a significant number of sickle cell patients living 100 miles or more away [from Little Rock]," Camp said. "Patients that we have driving this far seem to have a higher no-show rate and have no choice but to go to their local Emergency Department for a pain crisis."

Sickle cell patients often need to return after routine follow-ups for testing, imaging or infusions, which means more frequent travel. For patients living far from Little Rock, the process of arriving, receiving treatment and returning home can take up most of a given day.

"It can be extremely hard for these patients to drive long distances for multiple visits in a month, or even in a year due to socioeconomic factors," Camp said.

The national opioid crisis has brought increases in opioid-use related deaths and added to a hesitancy to prescribe pain medications. Since many sickle cell patients are diagnosed early in life, they become familiar with opioids quickly and are taught to ask for medications that they know have been successful in relieving their pain. Their pain tolerance also tends to be higher, meaning they may not initially appear to be in need of medication. Clinicians in those settings often are skeptical of pain complaints and suspect sickle cell patients are merely seeking drugs.

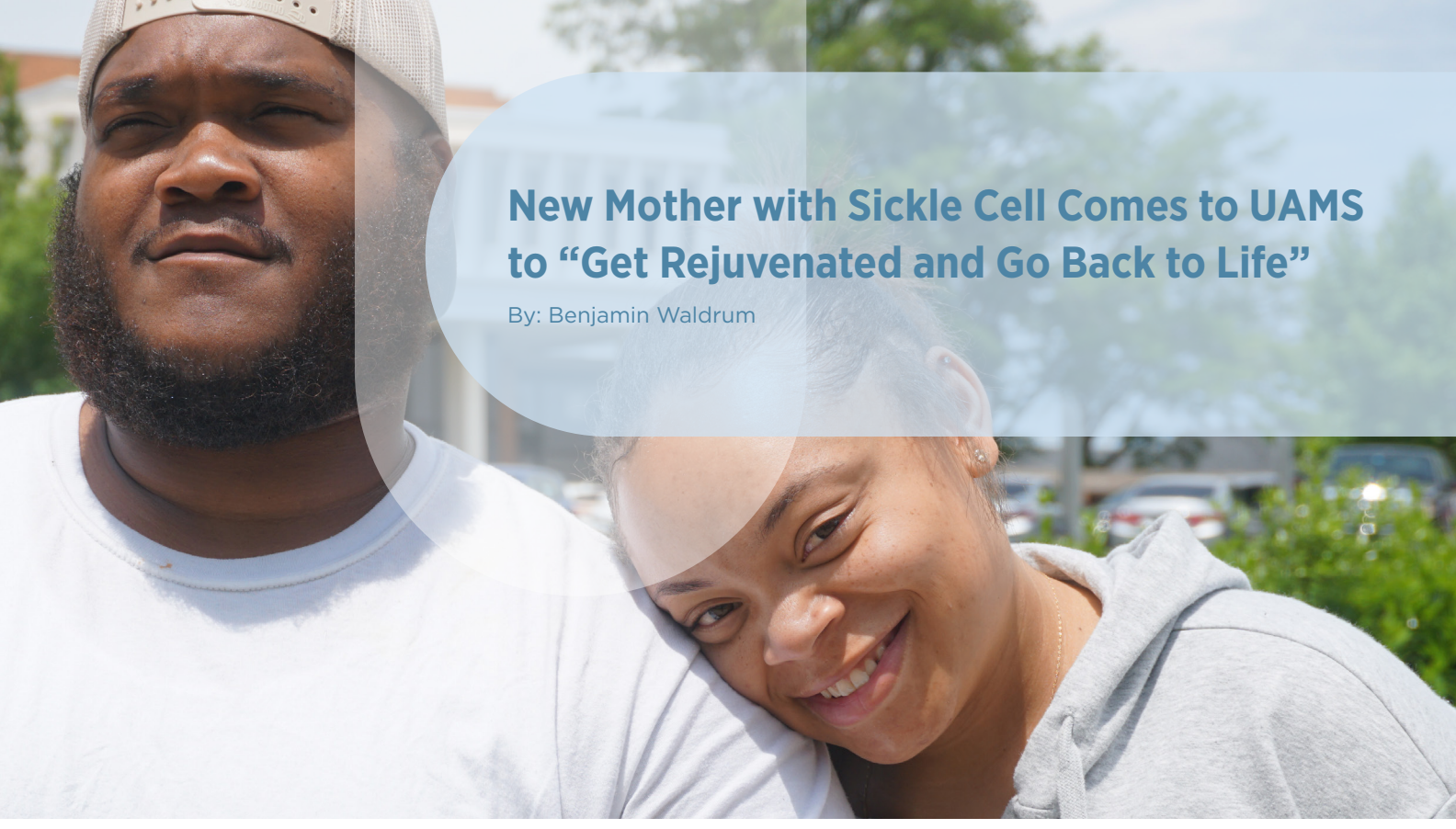
"Racial bias continues to play a role in patients getting the pain management they require," Camp said.

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 maintains more than 250 active patients across the state.

Sickle cell patients need more support going forward, Camp said. Among her recommendations were to increase the availability of stem cell transplants, which are the only known cure for sickle cell disease, and increase support for research and clinical trials. There is also a need to increase access through more informed providers, digital health options and education outreach.

"Even though things are improving, sickle cell disease continues to be understudied and lacks funding in all areas," Camp said.

The symposium closed with presentations on two recent treatments for sickle cell patients: voxelotor and crizanlizumab. Approved by the FDA in 2019, voxelotor increases hemoglobin, the protein in red blood cells that carries oxygen, to reduce anemia in patients. Crizanlizumab, also FDA-approved in 2019, inhibits platelet aggregation to help keep red blood cells from clumping together.



New Mother with Sickle Cell Comes to UAMS to "Get Rejuvenated and Go Back to Life"

By: Benjamin Waldrum

Sickle cell disease is just another part of everyday life for Jada Mosby, 24. And as a new mother, she doesn't plan on letting it slow her down anytime soon.

"It's just part of my life," she said. "It is my life, but it's nothing to me."

As a baby, Mosby was diagnosed with sickle cell beta thalassemia, which is a milder form of sickle cell anemia. Affected people have different mutations in genes that produce hemoglobin, the iron-containing protein in red blood cells that carries oxygen throughout the body.

Symptoms for sickle beta thalassemia range from very mild to somewhat severe, because hemoglobin production varies from person to person. More severe symptoms

resemble those of sickle cell anemia, including anemia, pain crises and increased risk of infection.

Mosby's symptoms are mild. She had very few pain crises as a child and has only been experiencing them recently, as she adjusts to more drawn-out apheresis treatments, which replace her red blood cells with new ones. Usually, she gets these treatments every four weeks, but they was recently extended to six weeks because her blood counts have been good.

"Before [May] I haven't had a pain crisis since I was little," Mosby said. "And when they switched me over to six weeks, that's when I started getting pain crises. I think it was just because they were switching me out, making me push a little farther."

The treatments have their ups and downs. She takes two pills a day, mostly to regulate the iron in her body after apheresis. Her husband, T.J., also 24, stays with her through each apheresis session. They commute from Conway, and it takes time out of their daily life. But Mosby takes it all in stride.

"I can just come [to UAMS] and take a nap — I call it my resting day," she said, laughing. "Just get rejuvenated and go back to life."

Overall, Mosby said she doesn't have too many complaints.

"My doctors have kept me well, so I haven't really have too many problems," she said. "I know for other sickle cell patients it's a little different, but for me, as long as I get my blood transfusions, and I drink water, taking the medicine, then I'm good."

She married her husband in 2019. They've known each other since they were children because their mothers were best friends growing up, Mosby said.

"Honestly it's easy to support her, just because I love her," said T.J. Mosby.

"To me, it's just a regular part of life," he said. "To me it's just, as a man, you do what you need to do to make the family as good as it can be, and to me this is just another part of it.

Their family is growing, too. In November, the couple welcomed baby A.J. into the world. He's now 8 months old, and Jada Mosby said having him was "a miracle."

"It was a shocker," she said. "Some doctors don't believe in having a baby when you have sickle cell. I know a couple years back I was told I couldn't have babies at all. I say it was a miracle, because I never thought I would have a baby."

Mosby first came to the UAMS Adult Sickle Cell Clinical Program as soon as she realized she was pregnant. She transitioned from the program at Arkansas Children's once she aged out.

Today, the couple is focused on living life to the fullest with little A.J. Mosby just started a job with the Arkansas Department of Human Services as a clerical worker. Regular activities outside of work include fishing, going to the shooting range and the park, or swimming.

With T.J. and now A.J. by her side, Mosby said she's in a good place these days.

"My future was having a baby, and I've already had him," she said. "I'm content with how I am right now. I had my baby, I'm good."

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