ADULT SICKLE CELL
Clinical Program

ANNUAL REPORT
2018 - 2019

UAMS

The **University of Arkansas for Medical Sciences Division of Hematology and Oncology in the Department of Internal Medicine** has partnered with the **Center for Distance Health** to create a statewide system of support for patients with sickle cell disease, 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 wellbeing.

Curtis Lowery, M.D.
Medical Director, ANGELS/
Center for Distance Health

Tina Benton, R.N.
Director, ANGELS/Center
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Collin Montgomery, APRN
UAMS Adult Sickle Cell
Clinical Program

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From the Director

Growth that is both deep and broad continues to shape and define the Adult Sickle Cell Clinical Program. Being present at the creation of the program in 2014 has afforded me the chance to see that happen.

We're not stopping though. We are continuing to build the program and to extend our reach to pockets of new patients. Our goal this year is to make sure all the program's patients keep experiencing continuity of care when moving from Arkansas Children's Hospital to UAMS or another provider.

The program recently has absorbed at once about 30 new patients from the Central Arkansas area who were receiving care from an independent provider who retired. We welcome them with the confidence they will enjoy the same quality of care received by our patients who have been with us since the program's start.

With the opioid crisis and increasing awareness of its social costs, many practitioners have been reluctant to prescribe important drugs for those patients. While we understand their reticence, especially since as practitioners many of them don't have the resources to monitor opioid use by patients, we feel well-positioned to help them with pain crises in a responsible way.

It's with those clinicians and our patients in mind that we applied for and recently received a grant of funds from the UAMS Translational Research Institute to develop a Clinical Decision Tool. The tool will guide outpatient opioid management among the clinic's patients. It will be implemented for all patients being prescribed less than 90 milligrams of morphine equivalents per day.

The prescribing protocols for outpatient care are very limited, and most of them have been developed for other chronic pain patient populations and then applied to sickle cell disease. We want to develop prescribing practices specifically for sickle cell patients and then share that with other Arkansas clinicians outside of UAMS. You can read more about the tool later in this annual report.

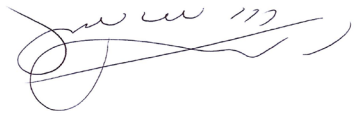
Arkansas' adult sickle cell patients are not just concentrated in one or two areas of the state. Because Arkansas remains a predominantly rural state with a dispersed general population, local access to specialists is often very limited.

A large percentage of the family medicine residents trained at UAMS and its Regional Campuses throughout the state end up staying and practicing in Arkansas. We are working closely with the Regional Campuses to make sure those residents understand sickle cell disease and how to treat it. That will help ensure in the future that the physicians in the state's communities will be able to provide better care outside of UAMS when they complete their residencies.

Finally, a new drug therapy for sickle cell disease using glutamine recently was approved by the U.S. Food and Drug Administration for clinical use. Another drug for treating sickle cell anemia, GBT440, has a lot of promise, and we are looking forward to its approval in the near future.

With variable success throughout the ages, humans have created financial and social networks grounded in the ethical obligation to help each other to compensate for what fate has dealt some of us. Our Sickle Cell Program is the embodiment of this commitment toward each other that was enacted into state law and the structure of our public service.

As we go into our sixth year, I can say this program is growing and fulfilling the mission for which it was created and serving the adult sickle cell population in Arkansas with a dedication to excellence that makes it a hub for patients and health care providers alike.



Issam Makhoul, M.D.
Director, UAMS Adult Sickle Cell Program

Spotlight: Collin Montgomery

As an APRN in the UAMS Adult Sickle Cell Clinical Program for three years and as APRN coordinator for the program for almost a year, I've helped to facilitate change. This year my focus has been program expansion, advocacy, and education.

Fortunately, the program expansion this year has given me the ability to see up to 30 more patients a month. The program has experienced an influx of outside referrals from providers who typically have provided pain medicine to sickle cell patients in the past. The opioid epidemic caused physicians and other providers to become increasingly reluctant to prescribe opioids, so they are referring more patients to us.

I work tirelessly to break down the stigma of being drug seeking, which is the biggest obstacle to care I've seen sickle cell patients encounter recently. That stigma can be influential on the care that patients receive. Much of the stigma stems from a lack of education about the disease. Any time I can share information about sickle cell and help to eliminate stigma, I'm always excited to do that.

Professional education in sickle cell in medicine or nursing often is minimal because it's an orphan disease that doesn't affect that many people compared to the general population. You find the bulk of your medical education on conditions and diseases like hypertension, diabetes and cancer that effected a larger group of people. Annually, I provide education to people across various health care professions in the management of the sickle cell patient.

Pain is likely the most well-known complication of sickle cell. Everybody knows that sickle cell patients have pain. There is much more to this disease and patient population than pain. I focus on providing care and educating other professionals on giving care that is holistic. It's not uncommon for people with chronic pain to have stress disorders. We watch for these and manage them when needed. Stress can be a trigger for a pain crisis, and many patients recognize the correlation between their stress and increased pain.

Ultimately my goal is for my patients to live the best life, and this can only be accomplished with holistic management. It's helping them cope with their emotional and behavioral struggles as well as advocating and educating others about sickle cell disease so when patients encounter problems, providers understand what they are going through. We've worked hard this year to reach these goals, and we will continue to strive for excellence for our patients.

Collin Montgomery, APRN
APRN Coordinator, UAMS Adult Sickle Cell Program

Living with Sickle Cell, Pine Bluff Woman Retains Joy

Doctors told her mother she wouldn't live past childhood. But Doris Carter proudly announces that she has her hands full at age 52 working as a nurse's aide in Pine Bluff, having raised two daughters and now keeping up with seven grandchildren.

When she was 3, Carter was diagnosed with Sickle Cell Anemia, an inherited blood disorder that causes red blood cells to become stiff and c-shaped like a sickle instead of round. That makes it difficult for the cells to pass through tiny blood vessels, causing many complications including painful flare-ups that require hospitalization.

Carter remembers having painful episodes in childhood and surgery to remove her spleen to help reduce attacks. Today, she credits her longevity to taking good care of her body.

"I eat well and I'm active," Carter said. "I don't misuse my medicine. I'm fortunate enough that I only have to come in to the hospital about twice a year."

Carter has a good relationship with her team of health care professionals. Leigh Ann Wilson, a licensed clinical social worker in the UAMS Sickle Cell Program, said Doris acts as her own advocate. That, she said, is crucial to successful treatment.

"She communicates what is important to her," Wilson said. "There are textbook suggestions, but every patient is different. Doris works with us to tell us what will work for her and what will not. I think that's one reason she does so well."

Carter also pays close attention to signals from her body. She said the pain is almost always there, but many times it's manageable enough for her to keep doing her day-to-day activities. When it gets worse, she knows it's time to slow down. Her grandchildren range in ages from 10-months to 10 years. She sometimes follows the oldest to dance competitions.

"I can't help but holler sometimes when I see them perform," she said with a chuckle. "They sometimes ask me to hush. But on those days that I have no pain, I'm dancing like Michael Jackson because it feels so good to be pain free."

Wilson often refers to patients like Carter when counseling other patients. In addition to treating patients at UAMS, she works with sickle cell patients at Arkansas Children's Hospital. Stories like Carter's give people hope.

"One of my favorite parts of my job is getting to follow my patients as they transition to the adult clinic," Wilson said. "It's great to be able to tell them that they can live full and happy lives."

UAMS opened an Adult Sickle Cell Clinic in 2014. Since then, hundreds of patients living with the disease have taken advantage of the Sickle Cell Clinic at UAMS, including a call center that is staffed by a panel of nurses. The number is 1-855-SIC-CELL (742-2355).

"I EAT WELL, AND I'M ACTIVE"

Transition Project:

Patients are treated at Arkansas Children's Hospital (ACH) until age 21. On turning 21, they are transitioned to an adult health care provider. UAMS works with ACH to ensure that transition to adult health care is a smooth and organized process.

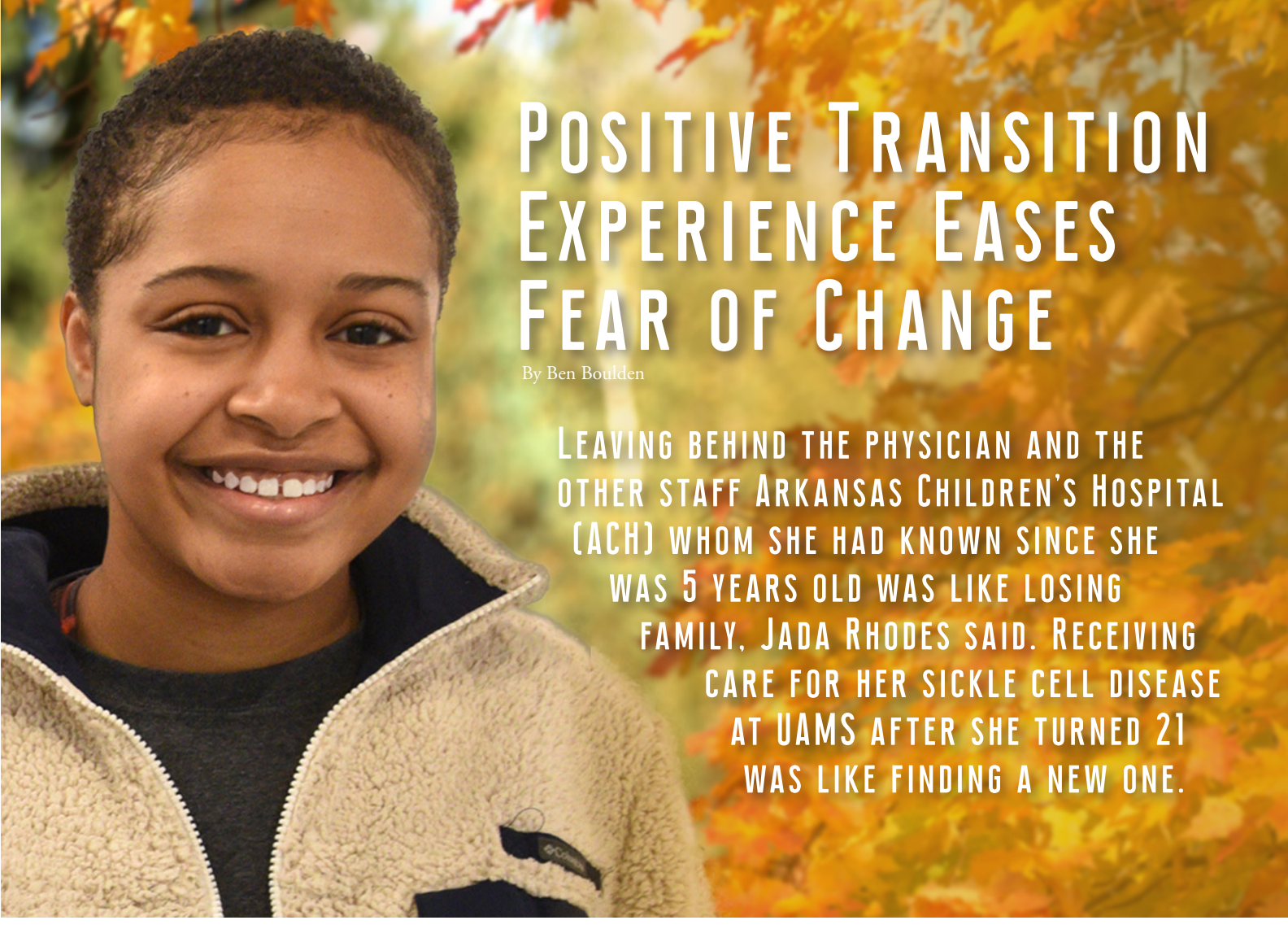
One way we work toward that goal is by having the social worker from the Adult Sickle Cell Clinical Program work in the ACH sickle cell clinic, meeting each patient that is nearing transition. During those encounters with each patient at ACH, the social worker assesses the level of disease-specific education needed. It is important that patients entering adulthood are knowledgeable about their disease and how to be their own advocates.

The UAMS social worker and the pediatric team have implemented an educational program specifically to help patients prepare for the transition. The program makes certain every patient receives an education on all aspects of their disease. There also have been web-based patient education modules developed by the UAMS Sickle Cell team for this purpose. The social worker assists patients with establishing an adult primary care provider in their community, as well as making their initial appointment at UAMS Sickle Cell Clinic.

Another way we work toward the goal of a smooth transition from pediatric to adult care is conducting a biannual transition meeting in which the UAMS social worker, and advanced practice registered nurse (APRN). Meet with the pediatric sickle cell team at ACH to review patients who will make the transition to UAMS within the next six months. The meetings help establish the continuity of care for patients during that time.

Thirty-eight patients have transitioned their care from ACH to UAMS since the transition program began.

Currently, 70 patients are age 16 or older and interact with the UAMS social worker during ACH clinic appointments.



Positive Transition Experience Eases Fear of Change

By Ben Boulden

Leaving behind the physician and the other staff Arkansas Children's Hospital (ACH) whom she had known since she was 5 years old was like losing family, Jada Rhodes said. Receiving care for her sickle cell disease at UAMS after she turned 21 was like finding a new one.

"It's not as bad as you might think it would be," Rhodes said. "They can become your family, too, just as easily as the folks at Children's did."

Sickle Cell patients are treated at ACH until age 21. On turning 21, they move to an adult health care provider, the UAMS Adult Sickle Cell Clinical Program. UAMS works with ACH to ensure the transition is an organized process. Rhodes said her interactions with social worker Leigh Ann Wilson started when she was 18. Those interactions were positive and reassuring to her.

Wilson frequently would visit with her when Rhodes was having a pain crisis that required her to seek treatment in the ACH Emergency Department.

Moving from the sickle disease treatment program at Children's to UAMS when she came of age nevertheless was a period of adjustment for Rhodes.

"THEY CAN BECOME YOUR FAMILY, TOO, JUST AS EASILY AS THE FOLKS AT CHILDREN'S DID."

"I personally don't like change, if I have a choice; but my sister did a capstone research project for her college degree. She looked at sickle cell anemia and was in the clinic for almost a year and knew everybody. She told me all about the program and the staff at UAMS. I like it now," Rhodes said. "I've got to get used to change. I can't be stubborn. That's life."

Rhodes was diagnosed at age 5 with sickle cell disease with an SS hemoglobin type. Both her parents carried the genetic trait for the disease. During the following 16 years, the clinicians at ACH treated her and supervised her care.

Rhodes said she had few pain crises when she was younger and would sometimes go as long as a few years between hospitalizations. As she has matured, the crises have become more frequent. Rhodes can have as many as two in one month, and as recently as the summer of 2018, just before the transition, she was in and out of the hospital with repeated crises for two months.

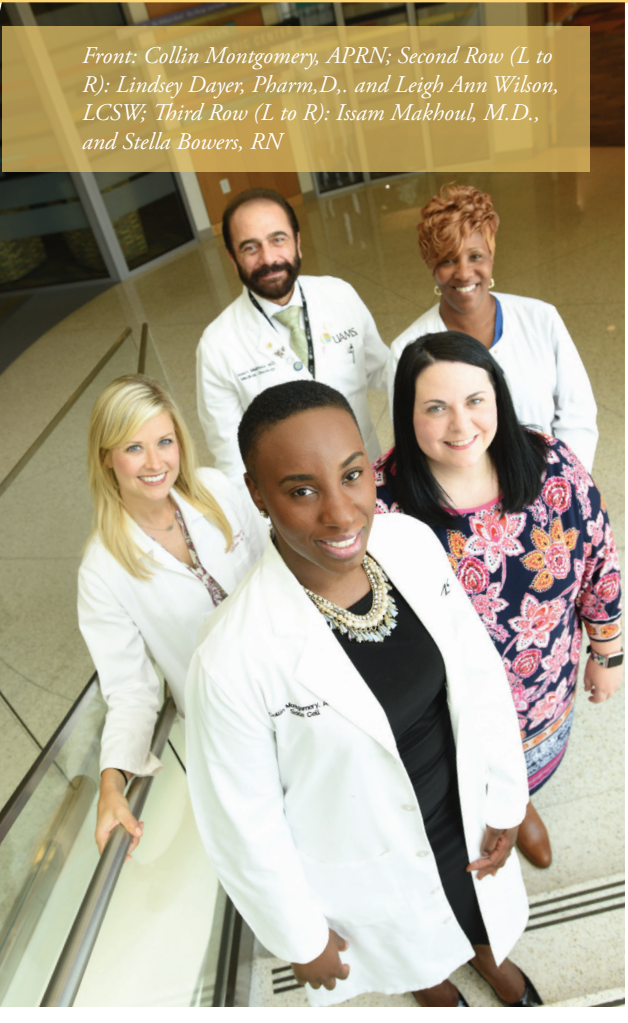
She works at a large sporting goods retail store and had to take a medical leave of absence from work. Fortunately, she wasn't enrolled in summer classes, so her education wasn't interrupted.

Rhodes said she's found ways to cope with her sickle cell disease while studying and has continued to use those techniques as she works toward a bachelor's degree in nursing at the University of Arkansas — Pulaski Technical College.

"It's harder to stay in school, but I've played the catch up game since I was younger, so I'm pretty good at teaching myself stuff on my own so I can stay caught up," she said.

Similarly, Rhodes said she's careful to stay hydrated and maintain a healthy diet to minimize the risk of a pain crisis.

Adult Sickle Cell Multidisciplinary Clinic



Front: Collin Montgomery, APRN; Second Row (L to R): Lindsey Dayer, Pharm,D,. and Leigh Ann Wilson, LCSW; Third Row (L to R): Issam Makhoul, M.D., and Stella Bowers, RN

The UAMS Adult Sickle Cell Clinical Program is a multidisciplinary clinic for adult patients with sickle cell disease. The clinic services patients from across the entire state of Arkansas.

The frequency of patient visits is based on the severity of the disease. They can range from monthly to annually. Comprehensive care is provided based on the individual needs of each patient. The UAMS Adult Sickle Cell Clinical Program keeps the patient's primary care provider informed of their sickle cell management.

The **Multidisciplinary Clinic of the Adult Sickle Cell Clinical Program** at UAMS includes a team of hematologists who are led by Issam Makhoul, M.D. The hematologists are physicians that specialize in blood disorders and diseases.

A nurse practitioner, Collin Montgomery works in collaboration with the team to deliver and facilitate holistic care in the outpatient setting.

A licensed clinical social worker, Leigh Ann Wilson assists patients and their families regarding social and emotional support, health-related expenses for the under/un-insured, transportation costs and employment options. She also serves as the cornerstone in facilitating successful transition of care from Arkansas Children's Hospital to the adult setting.

A registered nurse, Stella Bowers, provides care to patients in the outpatient setting. Additionally, she serves as community outreach coordinator. She establishes and fosters relationships between the clinic, community, and health care providers around Arkansas. She is also the liaison between the call center staff and the sickle cell team.

A pharmacist, Lindsey Dayer, Pharm.D., provides medication management through comprehensive medication reconciliation and medication counseling. She also assesses the effectiveness of medication.


1558
TOTAL SURVEYS
308
TRIAGE
1,078
DISEASE/HEALTH INFORMATION
46
REPORTING OF TREATMENT EVENT
2
PLACE ON REGISTRY
9
MD CONSULTOR TRANSFER
11
N/A OR NOT DOC

Call Center

The Sickle Cell hotline is hosted 24 hours a day, seven days a week by the Angels Call Center. Patients can call in with immediate problems, which are triaged by the Call Center 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, has reduced admissions and ED visits. The triage call center has provided an option other than the ED and is available during nights and on weekends when the clinic is closed.

This past year we received a unique call from a physician in Alaska requesting assistance in caring for a sickle cell patient in his care. The call center notified our APRN immediately, and she spoke with the M.D. and gave her expert advice in caring for the patient. This service wouldn't be available if not for the 24-hour call center. We also had a patient call for assistance in finding care as he moved out of state. The patient was given several options of care. These examples show the uniqueness and assistance available in the 24-hour call center. The call center provides an important component to the Sickle Cell 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.

Telehealth Support

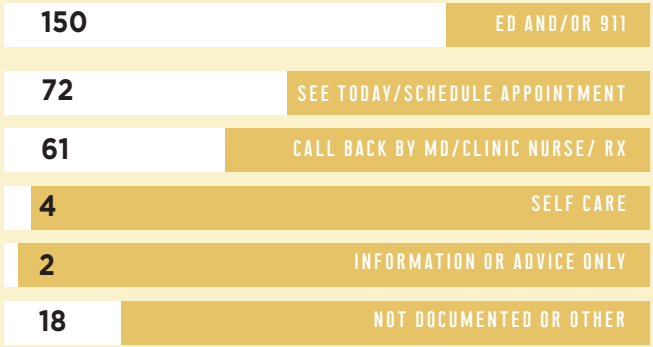
24/7 Call Center with Sickle Cell hotline

Staffed by experienced RNs that can offer:

- Patients, families 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, prevent crisis
  - Second level triage (calling Sickle Cell Team Member) before sending patient to ED → giving alternatives to ED visit when appropriate
- Doc to Doc consults - supporting PCPs and ED physicians that are caring for SC patients across the state

2018-19 Fiscal Year Cumulative Total

TRIAGE OUTCOMES



TOTAL: 307

DISTINCT VS. REPEAT REQUEST

Education and Outreach

Outreach in the UAMS Adult Sickle Cell Program

Part of the mission of our program is to spread awareness through visiting health fairs, schools, churches and other venues raising awareness of sickle cell disease and the Adult Sickle Cell Clinical Program. In the past year our outreach has changed slightly. We have been more focused on building our relationships with providers and other health care professionals. We discovered that most of our new patient referrals in 2017 -2018 came from other providers that had encountered us at a conference or fair. We will still work to raise awareness in the community through fairs and information to organizations on request.

UAMS continues to collaborate with Future Builders and Little Rock Black Nurses Association of Arkansas to organize a yearly Symposium. Our focus at the third annual Sickle Cell Symposium was on Sickle Cell: Mind, Body and Soul. One speaker, Shamonica Wiggins, a 29-year-old sickle cell patient, discussed the importance of maintaining good mental health while living with sickle cell disease. In her presentation Sickle Cell: Freeing Your Mind, she discussed her personal story of struggling to stay mentally healthy. Wiggins described how much better her life was after admitting she had problems with stress and depression and how her hospitalizations and opiate use decreased. She still battles crises and has been hospitalized, but she stated she was living her best life now. Our fourth annual symposium is coming up, please save the date, Sept. 17, Sickle Cell: Past, Present and Future.

The look of outreach may change, but our focus still remains to provide multidisciplinary care to Sickle Cell patients, awareness to the community and assistance to all providers in caring for sickle cell patients in the state of Arkansas and/or anywhere else we can assist.

Sickle Cell Support Services

There was a major change in the sickle cell community in our state. After nearly 15 years in the community, Sickle Cell Support Services has closed. Sickle Cell Support Services or SCSS started in 2004 and was co-founded by Germaine and LaKisha Johnson. The organization started as a support group, and evolved into supportive services, advocacy and much more. Germaine Johnson, the founder, lost his life due to the complications of sickle cell in 2014. The late Germaine Johnson played a major part in the establishment of the adult clinic. We will always honor him for his diligence in fighting to make health care better for himself and his fellow sickle cell cohorts. In the last five years his widow and co-founder, Lakisha Johnson continued to carry the torch and has had a major, positive impact in aiding the sickle cell community.

Lakisha stated, "This was one of the most difficult decisions that I have had to make, but I made it after a much-needed conversation with my sons, close friends and family members and a vote from the board. The decision was made." When asked if she was worried about support services in the state of Arkansas, LaKisha said, "No, I am not. A champion always arises, sometimes that doesn't occur until someone else gets out of the way. We have comprehensive programs at UAMS and Arkansas Children's Hospital, which provide quality medical care to our sickle cell consumers."

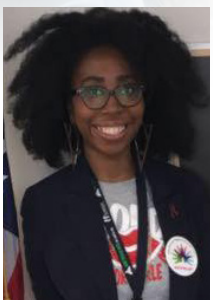
It was a pleasure to work with them, and we are so grateful for all that they have done for the sickle cell community. We thank them for all they have done for our patients and the adult clinic. Sickle Cell Support Services will be missed in the community, but never forgotten. Their motto, "We Suffer, We Fight and We Win" will be pressed in our hearts always.

Regional Program:

In January 2018, the UAMS Sickle Cell Clinical Program entered into a partnership with the UAMS South Central Regional Campus in Pine Bluff. The partnership provides education on the management of patients with sickle cell disease to the first-year medicine residents. Education is delivered using an online and live model. The online component is separated into five sickle cell-related topics. Each online component is followed by a didactic component that is delivered via teleconference by a member of the UAMS Sickle Cell Clinical Program. The family medicine residents are presented with case studies, brief review of the online content and a time to discuss sickle cell disease management. We started our second cohort March 2019, and look forward to beginning our first cohort with the UAMS Southwest Regional Campus in Texarkana in the summer of 2019.

The aims of these educational efforts are two-fold. They help to develop and foster a relationship with future family medicine providers and to equip them to confidently and competently care for sickle cell patients. With sickle cell disease being an orphaned disease, providers are often limited in their exposure to the disease and its management. The partnership between the UAMS Adult Sickle Cell Clinical Program and providers will help to bridge this gap and develop and foster highly competent primary care providers.

SYMPOSIUM SPOTLIGHTS
Psychology of Sickle Cell Disease



By 2014, Shamonica Wiggins had reached a point where she couldn't cope with her sickle cell disease. She felt lost and defeated until a therapist helped her try a new approach.

Wiggins, 25 and a Dallas native, spoke Sept. 18 at the Sickle Cell Symposium at UAMS. She was one of two guest speakers at the gathering sponsored by the UAMS Adult Sickle Cell Clinical Program.

"Depression, too many meds, and I was in a bad place," Wiggins said. "I was always in the hospital. Eventually, I gave in and went to see the therapist. Once I did, I wondered why I had kept putting it off. It was a big help. She helped me look at things from a different perspective and weigh out things properly."

Wiggins was spending a week of each month in the hospital. She was always in pain and always hurting. The hematologist who regularly treated her told Wiggins she was so overloaded with pain medications that they actually were hurting more than helping her. Wiggins' physician convinced her that depression was a part of her problem.

Wiggins said as much as she could, she would hide her pain from her mother and family. That lack of communication along with mishandling stress in her life was causing more pain episodes and increasing their duration.

Regular therapy started to change her health for the better. Through better personal planning and time management, meditation, exercise and even hot baths, the frequency and lengths of hospital stays diminished. With her physicians, Wiggins put a care plan in place to help make sure she spent the minimum time necessary in the hospital, too.

"You're going to have bad days, and you need to manage your mental health just as carefully as you manage your physical

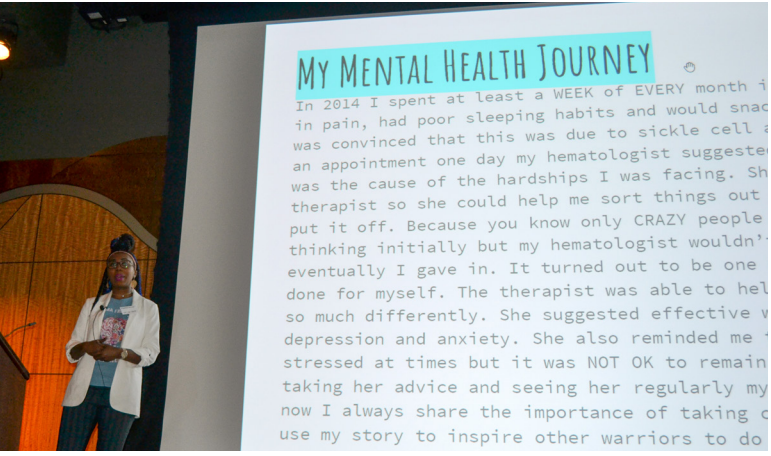


Photo Caption

health," she said. "It has really helped me in my journey as a patient. I learned a lot from my psychologist, especially the importance of telling the people around you how you're feeling. Otherwise, you're not going to move forward."

Wiggins has since founded #BoldLipsForSickleCell to educate and raise awareness of sickle cell disease through its advocates wearing bold lipstick colors.

"By doing this, they are making a loud and boisterous statement, which in turn gains attention along with conversations being sparked," the group's mission statement said.

Bold Lips also organizes public events to raise awareness and educate the public about sickle cell disease.

A superstitious belief that diseases like sickle cell and others are somehow a divine judgement on a person or people for moral failings persists even today, said the Rev. Johnny Smith, who was the pastoral speaker at the symposium.

"We need you to help us to eliminate that stigma," Smith said. "Individuals aren't always responsible for their circumstances. If we can eliminate that belief, then they can see the church as something that can help them."

Clergy and congregants can give counsel and just as importantly direct people who are physically or mentally ill to health care providers and therapists with clinical expertise.

People of faith who want to help need to engage those who are suffering but keep in mind their own limitations. Prayer and scripture alone may not be enough.

"Doctors are God's instruments to minister to our well-being," Smith said. "If you pray to God to heal you, you can't dictate to him how to heal you."

Leigh Ann Wilson, a licensed clinical social worker, also discussed local resources that can help patients cope with sickle cell disease. Wilson has worked in the UAMS Adult Sickle Cell Clinical Program for four years.

At the start of the symposium, Issam Makhoul, M.D., the program's director, addressed the audience, too.

"As we go into our fifth year, I can say this program is growing and fulfilling its commitment and meaning serving the adult sickle cell population in Arkansas with a dedication to excellence and being a hub for health care providers," Makhoul said.

TRI Grant:

In the UAMS Adult Sickle Cell Clinical Program, a multidisciplinary team and an expert advisory panel are developing a clinical decision tool to guide outpatient opioid management among the clinic's patients. The tool will be implemented for all patients being prescribed less than 90 milligrams of morphine equivalents per day.

Although a prescribing system exists for pain episodes in the inpatient setting, the standardized approaches for outpatient opioid prescribing are very limited. No standardized protocols exist. Adult sickle cell patients requiring acute inpatient management for three or more pain episodes per year have an increased risk of death when compared to other sickle cell disease patients receiving effective outpatient care. The care standard has involved combining opioid prescribing practices from other chronic pain patient populations and applying them to sickle cell disease.

Establishing a complete system for both outpatient and inpatient care will make prescribing practices consistent among patients experiencing pain. This will decrease the risk of death and improve patients 'quality of life. It also may mean primary care and other physicians in Arkansas will be able to use the tool to help their patients, giving them greater confidence as health care providers in treating adult patients with sickle cell disease

This pilot project has two goals: first, to develop the clinical decision tool; and second, to measure the effectiveness of the clinical decision tool. After implementation of this tool in our clinic, the program's goal will be to maintain and/or reduce the morphine equivalents patients receive while maintaining and/or improving their quality of life. Patients will be assessed at each clinic visit throughout the study period.

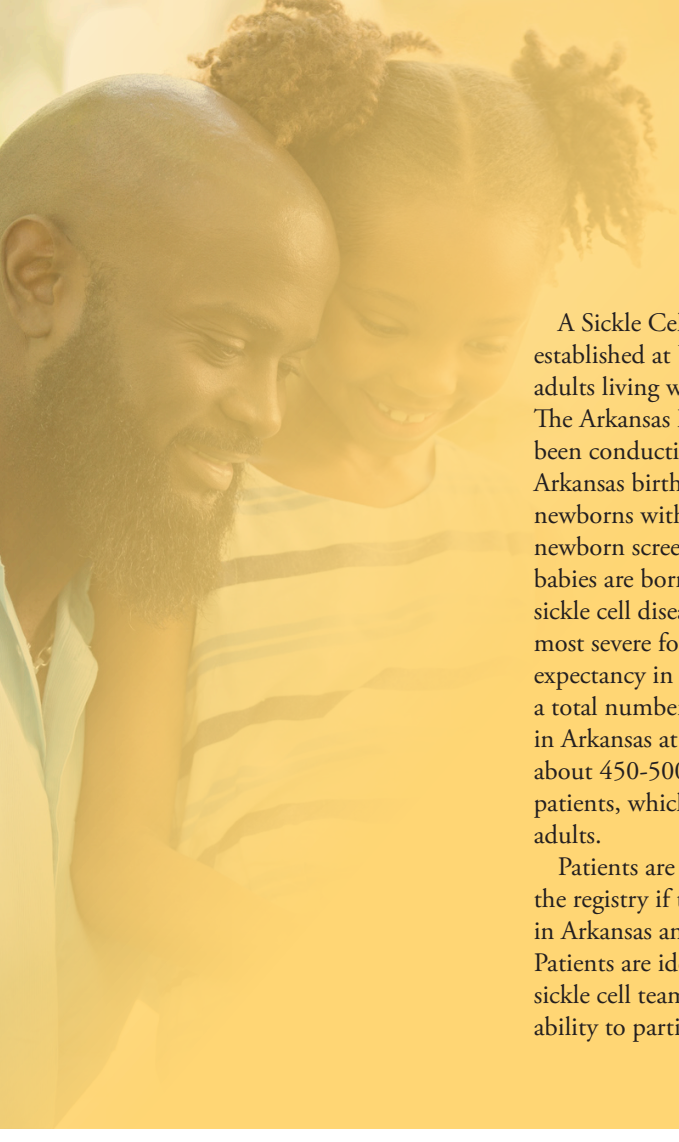
The research team will collect feedback internally and from other clinicians using the tool to continue to improve on it, increasing its effectiveness and positive outcomes for sickle cell patients. The data also will be shared with other clinicians outside UAMS. Just as importantly as guiding medication management in the clinical program is how the clinical decision tool will be used in continuing outreach efforts to Arkansas clinicians so they can be better informed and prepared to treat sickle cell patients with the best practices.

Needs Assessment:

Brittney Dennis

The UAMS Adult Sickle Cell Clinical Program received help from a graduate student at the Clinton School of Public Service, assessing the needs of sickle cell patients. Brittney Dennis, earned her master's degree in public service which required her to complete a Capstone Project. The UAMS Sickle Cell team submitted a proposal for a capstone project to have a needs assessment completed. A needs assessment was completed in the state prior to the clinic opening, so it makes sense to have another assessment to explore where the program needs to focus now. Brittney, collected data from April 2018-June 2018, which included both quantitative and qualitative data, by administering a 31 question survey to 20 clinic patients, and an eight question interview with five respondents by phone. Fifty-three percent of the patients lived in Pulaski County; 25% were 18-25 in age; 15% do not have health insurance; 20% do not have a primary care physician (PCP); 15% utilize the ER for most primary care needs; 35% cannot get appointments with PCP when wanted; 60% have difficulty finding a PCP; 20% feel their PCP does not care about them; 100% do not seek care from their PCP for SCD care; 50% avoid seeking health care, 45% have waited three hours or more in the ER for their pain to be treated; 30% feel the ER doctors or nurses do not believe they have bad sickle cell pain. This information is helpful for the sickle cell team as they work with the UAMS Regional Campuses to train the family medicine residents on how to treat and manage adult sickle cell disease.

53% Patients lived in Pulaski County	**20%** No PCP	**60%** Difficulty finding a PCP	**50%** Avoid seeking health care
25% Ages 18 to 25	**15%** Use ER for most primary care needs	**20%** PCP does not care about them	**45%** Waited 3 hours or more in the ER for pain treatment
15% No Health Insurance	**35%** No appointments with PCP when wanted	**100%** Do not seek care from their PCP for SCD care	**30%** ER doctors or nurses do not believe they have bad SC Pain



Sickle Cell Disease Registry

A Sickle Cell Disease Registry was established at UAMS to learn more about adults living with the disease in Arkansas. The Arkansas Department of Health has been conducting newborn screenings of all Arkansas births. Since 1988, it included newborns with sickle cell disease. From the newborn screenings, we know about 25 babies are born each year in Arkansas with sickle cell disease. Given that those with the most severe form of the disease have a life expectancy in the mid-40s, we can estimate a total number of people with the disease in Arkansas at 1,300. We also know that about 450-500 of these patients are pediatric patients, which means about 800-850 are adults.

Patients are eligible for participation in the registry if they are at least age 18, live in Arkansas and have sickle cell disease. Patients are identified for the registry by the sickle cell team at UAMS. Patients have the ability to participate in the data collection portion, as well as a one- time collection of a blood and urine samples. The blood and urine samples are being collected and stored for future research. Collection for the registry began in March 2015, and as of March 2019, 110 patients have consented to participate in the disease registry. Of the 110 patients, 95 patients have provided blood and urine samples. Reports for the data have been completed with all 110 patients and are represented in the following graphs.

Participants of the Sickle Cell Registry also are asked to complete a Quality of Life survey. The Quality of Life (QOL) survey is defined as an overall assessment of a person's well-being, which may include physical, emotional and social components as well as stress level, sexual function and self-perceived health. The QOL helps providers better understand the impact that sickle cell disease is having on a patient's daily life. The QOL ranges from 16 (worst possible) to 112 (best possible).

Disease Registry

77% State of Birth

Outside of Arkansas 23%

Highest Level of Education

Diagnosis

SS 54%

SC 25%

Beta Thalesmia 19%

HB-O Arab 2%

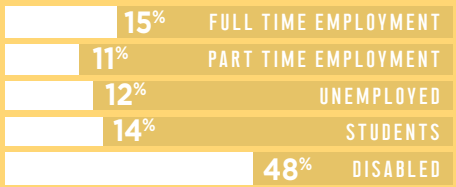
Type of Insurance

Medicaid 58%

Medicare 26%

Private 16%

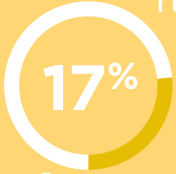
Employment



Reproductive

Complications

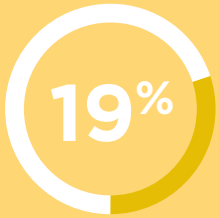
Acute Chest Syndrome



Priapism

Pulmonary Hypertension

Stroke/Transient Ischemic Attachk. Seizures



Iron Overload

Chronic Renal Failure

Gallstones/Cholelithiasis. Cholecystitis

Splenomegaly. Splenicsequestration. Hypersplenism

Leg Ulcers

Osteomyelitis

AVN

Quality of Life

Highest

Median

Lowest

AVERAGE

80.78

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