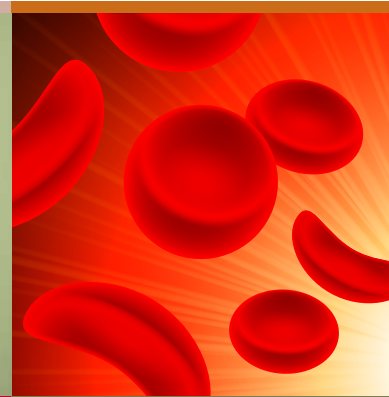


Sickle Cell



2015
ANNUAL
REPORT

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



Tina Benton, R.N.
Director, ANGELS/Center
for Distance Health



Issam Makhoul, M.D.
Director, Hematology/
Oncology Division
Internal Medicine

The UAMS Division of Hematology/Oncology 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.

From the Director

The UAMS Adult Sickle Cell Clinical Program was established in January 2014, with funds from the Arkansas Legislature and Arkansas Medicaid. For decades, Arkansas Children's Hospital has been caring for children with Sickle Cell Disease, but as the patients reached adulthood, there was no organized continuation of care, and many with the disease were lost to follow up. Now, we have the opportunity to continue evidence-based, quality care for adult Arkansans with this rare, genetic blood disorder.

This program would not exist were it not for the tireless grass roots efforts of Germaine and LaKisha Johnson of Sickle Cell Support Services, a non-profit organization that lobbied the state legislature for years regarding the need for a specialized clinic for adults with Sickle Cell Disease. Germaine had very advanced Sickle Cell Disease, yet was often seen at the Capitol, advocating for others with the illness. He died last year, but not before he saw his dream become a reality. The Black Caucus within the AR Legislature, and the Minority Health Commission were instrumental in making this program a reality.

Within UAMS, Chancellor Dan Rahn recognized the importance of the proposed Adult Sickle Cell Clinical Program, and has supported our efforts at every turn. The Division of Hematology/Oncology partnered with the Center for Distance Health to create a multi-pronged approach to caring for Arkansas's adults with this life-limiting genetic disorder. Drs. Issam Makhoul and Curtis Lowery (Division Directors of Hematology/Oncology and Center for Distance Health, respectively) are to be thanked for the support they bring to this initiative.

Patients with Sickle Cell Disease receive care at our Sickle Cell Clinic, within the Winthrop P. Rockefeller Cancer Institute. They benefit from care in our Infusion Center, where nurses infuse fluids, transfuse blood and provide pain relief. They visit our ED, where their painful crises and emergent needs are managed, and they frequent our Apheresis Unit, where much-needed red blood cell exchanges can take place. Our nurses and physicians care for the patients when they are admitted here, and our Call Center Nurses take calls from physicians from around the state, when patients are admitted elsewhere. Thanks to all the staff at UAMS who make the Adult Sickle Cell Clinical Program a success.

So far, we've interacted with 145 patients. We know of 4 deaths during the first year, in patients ranging in age from 30-60. Through this program we hope to reach as many as 900 adult Arkansans living with this disease, help them to live as long as possible, with as much comfort and support as possible. We have a solid start, and we are so grateful for all the support we've received along the way.

Sincerely,

Robin Devan, M.D.





UAMS Adult Sickle Cell Clinic **ChangesLIVES**

Little Rock's Jarques Smith, 24, who was diagnosed at birth, said discovering the clinic has helped provide a much-welcomed sense of stability. When a primary care doctor told him at age 12 that he didn't have sickle cell, he lost his insurance and managing the pain became hectic.

"I couldn't go to a primary care physician or clinic for my treatment, so I did go to the emergency room quite often," he said. The process was time consuming -- waiting to be seen, getting fluid injections, and receiving pain medication. And it often meant limited relief.

"Depending on how serious you are, they may keep you or let you go for the night. Usually when they let me go for the night, I'd end up right back in the

ER because of the pain. It's just like a cycle; you can't make it go away."

That made it hard to hold a job or be a student.

"There've been classes that I failed, jobs that I lost, because of crisis pain," Smith said. "I've had jobs and had to go into the emergency room, and I come back and I didn't have a job anymore. A lot of people overlook sickle cell because not a lot of people have it, and people don't talk about it as well. There have been doctors that came into the room and just swore up and down that I wasn't in pain, that I was just there for the medicine."

That started to change in the fall of 2013 when Smith met Robin Devan, M.D., on a trip to the UAMS emergency room.

“Once I came across Dr. Devan, it was better. She was a sickle cell doctor. She knew patients that had sickle cell. She told me that she really did understand how I was feeling and what I was going through, which I never had with all the doctors that I came across in the ER. Nobody ever understood the pain of a sickle cell crisis.”

Devan told Smith about the formation of the clinic,

“In the past, patients were sent off to a primary care provider as an adult with this disease. But it’s a rare disease. Primary care providers out in rural Arkansas might not take care of but one patient with this disease. So it puts a burden on that provider,” she said. Additionally, patients might change jobs and move, losing contact with their provider. Usually that results in frequent trips to the emergency room.

The clinic, which began in January 2014, and its associated programs aren’t meant to replace primary care providers, Devan said, but add “another layer of support for patients.” Sometimes that’s immediate care; other times it’s just a listening ear via the help line at 1-855-SIC-CELL (742-2355).

We get about 150 calls a month, and that’s 150 calls that used to never, happen” Devan said.

“That’s one of the things that I’m most proud of, that we have this opportunity as a sickle cell team to educate the patients,” Devan continued. Whether it’s about smoking cessation, avoiding inflammatory foods or just avoiding general life stress, conversations with patients have gone a long way.

“Stella, R.N. and sickle cell clinic nurse, is a wonderful ear on the end of the line, and a lot of patients have come to call her for things other than their sickle cell pain.”

For Smith, the programs have allowed him to stay active. In addition to being on track to graduate with a business degree next year, he works for a nonprofit that engages at-risk teen boys in service projects and provides mentoring and support.

“Everything’s just been a learning experience to me, it’s all new,” Smith said. “It seems like it’s just happened out of the blue, but I’m grateful for it.” ☾

“That’s one of the things that I’m most proud of, that we have this opportunity as a sickle cell team to educate the patients.”

Robin Devan M.D.

Overview

Sickle Cell Disease can cause many complications, from painful episodes often requiring hospitalization to bone infections, stroke and kidney disease. Not surprisingly, such complications are physically difficult for the individual and financially burdensome for the individual and the state. A compounding factor in the overall management of SCD is that many of the patients live in rural, underserved areas. There are at least 1200 Arkansans with the disease, and although this is a relatively small population, those with severe disease seek emergency care frequently due to pain. Often times, this is due to not having a Primary Care Physician to manage their high-risk, chronic condition. Those patients with the severe form of the disease can require complicated case management, and carry a stigma of being ‘drug seekers’.

In 2010 an Arkansas Legislative Task Force on Sickle Cell Disease was created. The task force included representatives from the following:

- ≡ Sickle Cell Support Services of Little Rock,
- ≡ Hematologists from ACH and UAMS,
- ≡ Partners for Inclusive Communities/UAMS
- ≡ A former Surgeon General

- ≡ Arkansas Foundation for Medical Care
- ≡ Office of Minority Health/Arkansas Department of Health
- ≡ Arkansas Minority Health Commission
- ≡ Mutual Self-Help Support Group of Pine Bluff
- ≡ Newborn Screening Program/Arkansas Department of Health

The Task Force reported to the Arkansas General Assembly, outlined the problems causing disparity in healthcare to this population, and made recommendations for a solution. As a result, in 2012 the University of Arkansas for Medical Sciences (UAMS) was given the opportunity to coordinate the care of adults with sickle cell disease in Arkansas. The legislature recognized a need among this underserved, minority population, and generously provided funds for UAMS to develop and nurture a program that would benefit Arkansans suffering with Sickle Cell Disease. Medicaid continued that funding. The UAMS Division of Hematology/Oncology 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, not only will this minority population experience relief of suffering, but the entire state will also experience an improved well-being.

The UAMS Adult Sickle Cell Clinical Program launched in Jan 2014 and includes: a Transition Clinic facilitating patient transition from pediatric to adult care, a sub-specialty multi-disciplinary clinic, best practices treatment guidelines for healthcare

providers, community outreach, a Disease Registry, a directory of Arkansas Healthcare Providers that manage Sickle Cell patients, and a 24/7 hotline to support the program and serve as the access point for Sickle Cell patients and healthcare providers across the state.

Welcome our newest team member!

Veronica D. Morton, R.N.,
M.S.N., A.C.N.S.-B.C., A.P.R.N.



Program Team

Left to right: Robin Devan, M.D. (Program Director); Stella Bowers, R.N. (Clinic/ Outreach); Donna J. Richardson, R.N. (Program Mgr, ANGELS/CDH); Leigh Ann Wilson, L.C.S.W. (Social Worker)



"The UAMS Cell Therapy Apheresis team consists of 6 nurses and 5 physicians, who provide red blood cell exchange as maintenance therapy to prevent sickle cell crisis in those adults who have a history of iron overload, stroke or acute chest syndrome. Patients return approximately once a month for their exchange and spend 2-4 hours with our team."

Michele H. Fox, M.D.
*UAMS Director of Cell
 Therapy and Transfusion
 Medicine*

Sickle Cell Support Services



"Having a Sickle Cell Adult Clinic now up and running with a wonderful staff behind it, is amazing. For the first time ever, it gives more hope,

something to look forward to. I can see more lives being changed and saved. The clinic is so important to the future of our children with Sickle Cell and to our adults that are living longer. I am so thankful to God, and I am so happy that we found a wonderful doctor, and wonderful nurses and all the key components to keep this clinic up and running."

Germaine A. Johnson Sr. *(deceased) patient,
 co-founder of Sickle Cell Support Services*

"Although Germaine is gone his fight continues. As Executive Director (of Sickle Cell Support Services) I will continue to fight for equitable resources, better health care practices and more research for individuals living with sickle cell disease. This isn't our platform, this is our life."

LaKisha Johnson—*Sickle Cell Support Services*

Transition Project

Patients, as they grow to adulthood, are transitioned to the adult healthcare system gradually, and in an organized fashion.

Biannually, the UAMS Social Worker (SW) and Advanced Practice Registered Nurse (APRN) meet with the Pediatric Sickle Cell team at Arkansas Children's Hospital (ACH) to identify patients who are reaching adulthood. The UAMS SW meets with patients during clinic appointments at ACH to prepare them for transition. Records are transferred to UAMS, and UAMS SW assist in scheduling the patient's initial clinic visit to UAMS. The SW assists patients in identifying a primary care physician in the patient's community when available.

"I am an adult sickle cell patient at UAMS. I know it will be a long hard road, but with understanding from both staff and patients, we can overcome the odds. UAMS is kind of like a school in a way, both staff and patients learn together and all work towards one goal. The goal of understanding illness and treatment."

Christopher Akins
Helena, Arkansas



"The UAMS sickle cell program is providing a much needed multidisciplinary team approach and filling a previously unmet need in Arkansas for the care of adults with sickle cell disease. Leigh Ann Wilson, our social worker, sees patients at both Arkansas Children's Hospital and at UAMS to facilitate the transition process. I appreciate that the program is improving access to care for an underserved patient population in Arkansas and offering access to erythrocytapheresis to patients who need it."

Suzanne L. Saccente, M.D.
Assistant Professor of Pediatrics
Arkansas Children's Hospital

UAMS Multidisciplinary Clinic

The UAMS Adult Sickle Cell Clinical Program provides a Multidisciplinary Clinic for adult patients with sickle cell anemia from all over the state. A patient with more severe complications from the disease may receive more frequent visits as needed. On the basis of each comprehensive visit, a care plan for that patient is created to serve as a blueprint for the patient's medical care throughout the year and is communicated to each patient's primary care provider. The Multidisciplinary Clinic of the Adult Sickle Cell Clinical Program at UAMS includes:

- ≡ A physician to see patients, consult with other physicians at UAMS and around the state and provide leadership to the program.
- ≡ A nurse practitioner to see patients in both the inpatient and outpatient settings, respond to telephone calls from physicians or patients regarding sickle cell anemia and its various complications, manage the registry and explore educational and funding options for the program.
- ≡ A social worker to assist patients and their families with issues regarding health related expenses not covered by insurance, transportation costs,

employment options, facilitates the patient support group and social, emotional support. This team member is essential in the patient's transition from ACH to adult care.

- ≡ A community coordinator (RN) to connect the clinic to other health care providers around the state, help connect patients with the clinic and serve as liaison to call center and patient advocacy group.
- ≡ In July 2014, the UAMS Adult Sickle Cell Clinic added a board certified hematologist to its multidisciplinary team. Hematology fellows also work with the program, under the supervision of the hematologist.

The Sickle Cell Clinic has,
so far, reached

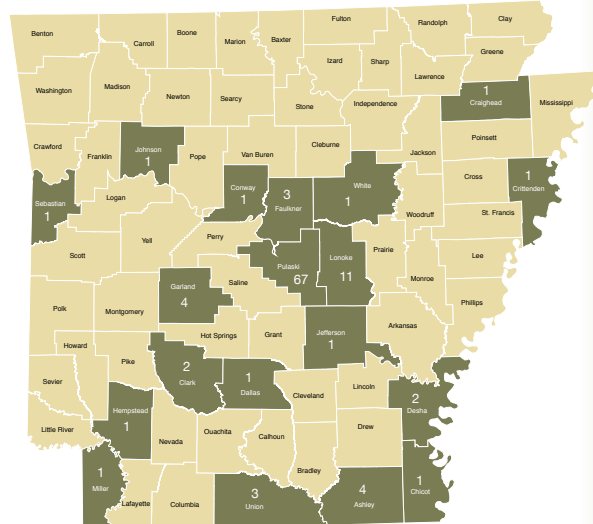
120 patients in 19 counties
in Arkansas



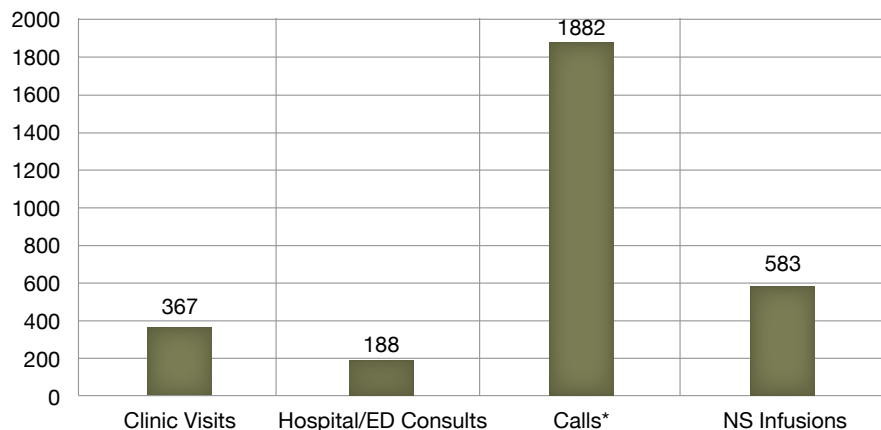
“One of the great programs UAMS offers to the Sickle Cell population is outpatient infusions. This program allows patients with sickle cell to receive IV fluids, along with pain medication – reducing the incidence of crises and hospitalizations. The patients respond well to the program, promoting compliance with treatment regimens, and overall wellbeing.”

Glen Lewis, R.N.
Infusion Room

UAMS Adult Sickle Cell Clinical Program Clinic Patients - Counties of Residence - 120



Fiscal Cumulative Total 2014-15



*Calls are total of Call Center, Clinic RN and Social Worker

Call Center



The Sickle Cell hotline is hosted by the 24/7 ANGELS Call Center, established in 2004 at UAMS to support a robust statewide telemedicine infrastructure. Calls received are from healthcare providers requesting advice on patient management, and from patients requesting appointments, asking questions regarding their disease, or experiencing a complication. Acute medical issues are triaged by the Call Center RN and advice is given regarding the level of care needed. Advice may include sending a patient to the emergency department (ED) for treatment, scheduling an appointment, or providing instruction for self-care at home.

Telehealth Support

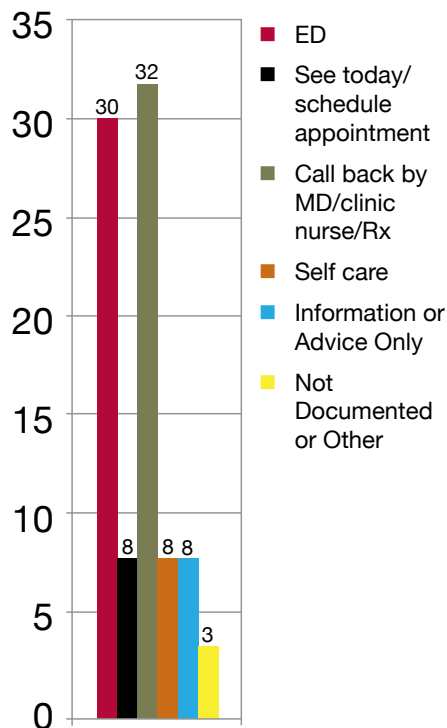
Giving the patients direct access to a triage nurse familiar with this disease and equipped with triage guidelines to give the most appropriate level of care, along with having a dedicated Sickle Cell Clinical Team to provide second level triage, is reducing ED visits in this population.

24/7 Call Center with Sickle Cell hotline

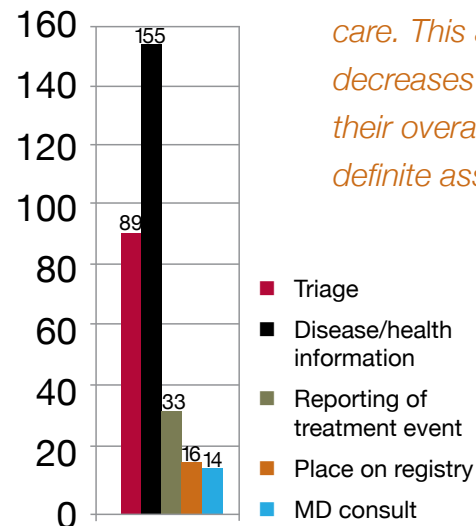
Staffed by experienced RNs that can offer:

- ≡ 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

Call Center - Triage Outcomes July 2014 to June 2015



Call Center - Caller Request July 2014 to June 2015



"I believe the Sickle Cell Call Center is an excellent resource for the adult Sickle Cell patients of Arkansas.

The service allows patients and their families to make a phone call and know they have a knowledgeable and caring RN to speak with regarding their disease process which alleviates fears and expedites appropriate care. This also fosters compliance, decreases ED visits and promotes their overall wellbeing. We are a definite asset to our patients."

Evonne Amerine, R.N.
ANGELS Call Center

Triage Outcomes

A review of 2014 (calendar year) Call Center Triage Outcomes was conducted and presented as an abstract to the American Telemedicine Association and accepted as an ePoster presentation at the 2015 ATA Annual Meeting. The ePoster was honored as one of the top four ePosters presented out of approximately 90 National entries.

A summary of the review:

In 2014 of the 306 calls the hotline received, 115 were patients needing triage for medical complications. Of the 115 triaged, 47 were sent to the ED for urgent treatment, 39 were scheduled an appointment, 29 were given self-care instructions and stayed home. There were 20 occasions where patients would have been sent to the ED but instead the Call Center Nurses were able to utilize 2nd level triage with a Sickle Cell Team member on-call and an alternative outcome resulted. Alternatives to the ED included clinic appointments, same day infusion clinic, or adjustment in pain medication. There were also 7 occasions where patients stated they would have gone to the ED had they not been able to speak to a

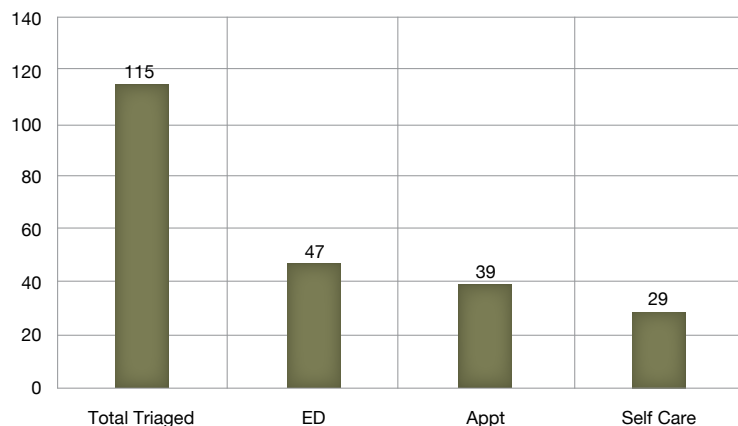
triage nurse. In total the Call Center was able to avoid sending patients into the ED on 27 separate occasions during 2014.

Estimated cost savings from avoiding 27 ED visits were calculated by using the National average costs for sickle cell patients. With an average ED visit costing \$1572, 27 visits avoided could have potentially saved \$42,633. The research shows (footnote 1) that 68% of ED visits of patients with Sickle Cell disease result in hospital admissions with each admission averaging \$21,679. So, our 27 avoided ED visits also likely avoided 18 admissions potentially saving a total ED and Hospital stay cost of \$432,855. (*see charts*)

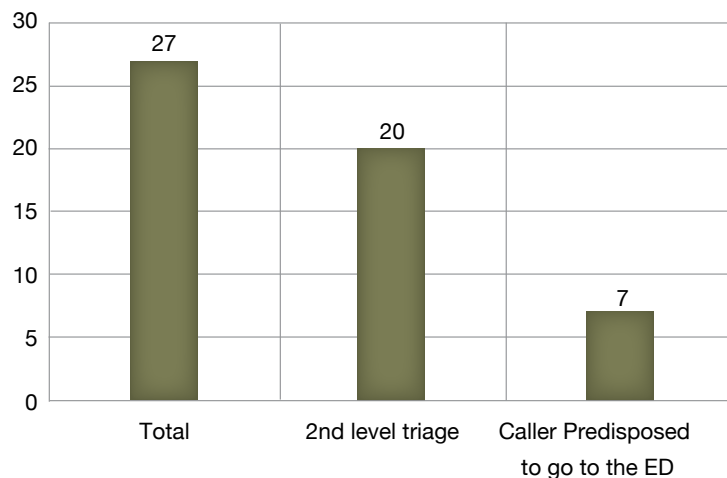
In 2014, the Call Center was
able to avoid sending patients
into the ED on

27 occasions

Call Center - Triage Outcomes 2014



Avoided ED Visits



Estimated Cost Savings

National Average Cost for Sickle Cell Patients

- ≡ Cost of ED Visit - \$1,572
- ≡ 68% of Patients seen in ED are admitted
- ≡ Cost of Hospital Admission (7 day, Reg room)=\$21,679

Estimated savings based on National Averages

- ≡ 27 avoided ED visits
 $27 \times \$1,572 = \$42,633$
- ≡ Potentially 68% of ED visits would have been admitted
68% of 27 = 18
- ≡ 18 potential admissions
 $18 \times \$21,679 = \$390,222$
- ≡ Ed + Admissions = **\$432,855**

References for National Averages for Sickle Cell cost:

'Health, United States, 2012. With Special Feature on Emergency Care': U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics; <http://www.cdc.gov/nchs/data/abus/abus12.pdf>

'The cost of health care for patients with sickle cell disease'; American Journal of Hematology. Vol. 84, Issue 6; Article first published online: 24 APR 2009 <http://onlinelibrary.wiley.com/doi/10.1002/ajh.21443/pdf>

'The Burden of Emergency Department Use for Sickle Cell Disease: An Analysis of the National Emergency Department Sample Database'; Sophie Lanzkron, MD, MHS, C. Patrick Carroll, and Carlton Haywood, Jr., PhD, MA; Am J Hematol. Author manuscript; available in PMC 2012 Aug 31.

Education and Outreach

The Adult Sickle Cell Clinical Program has several measures in place to help ensure that our patients receive standardized and comprehensive health care services that address their unique health needs. These include the previously mentioned call center triage guidelines, order set for inpatients admitted for sickle cell crisis, ANGELS guidelines for sickle cell disease in pregnancy and NIH guidelines for the management of sickle cell disease. The team works in collaboration with the primary health provider. Specialist and inpatient providers address these needs and attempt to prevent complications.

Healthcare Providers

In recent months, the program has started to address the sickle cell health informational needs of health providers around the state. UAMS Centers for Distance Health provides the opportunity for participation in 'Connecting Across Providers' (CAP), which is a statewide means of provider teleconferencing. The Adult Sickle Cell Clinical Program provides quarterly CAP teleconferencing regarding various aspects of sickle cell disease and treatment. These presentations are available to providers across the state for live viewing as well as availability for on demand

viewing. Providers can earn CEUs for education provided at these teleconferences. Dr. Devan has provided educational lectures to several groups here at UAMS, including medical residents in Emergency and Family Medicine. The team attends and presents at professional meetings and conferences. This is all in an effort to provide education about this patient population and standardize the care they receive. There are plans for continued outreach to health providers throughout the state. The goal is to determine the sickle cell knowledge deficit for providers, provide continued, disease specific education and eventually identify a core group of providers across the state to help care for this population. Recommendations for the management of sickle cell patients will be available.

Case consultation, training, and program information is available for health care providers across the state through the ANGELS Call Center Sickle Cell hotline 1-855-Sic-Cell (742-2355). Our website, sicklecell.uams.edu is another way healthcare providers, patients, their families and the community can get information regarding our program, disease information, educational opportunities and even social media connections related to sickle cell.

Patients and community

Patient, family and community education are achieved through involvement in community activities, including health fairs and through the monthly sickle cell patient support group.

The Social Worker and RN for the program facilitate a monthly support group meeting for patients and family members. The group is called 'Excelling with Sickle Cell Disease' and meets for an hour and a half, every 3rd Monday of the month at the Main Library in Little Rock. The group ranges in attendance from month to month, and has had 12 patients and 5 family members attend at least one group, over the past year. The group is an open group with a relaxed format. The group members are free to discuss any topics they wish and can share with the group about their life, family, and health issues. The Social Worker and RN identify topics for each month to help facilitate discussion and grow their knowledge of sickle cell disease. The group is promoted to the patients during clinic visits, an email reminder if patient consents to monthly email reminder, and phone call reminders.

Figure 1: Outreach Efforts July 14-June 15



Outreach: Primary Care Physicians of Arkansas Surveyed

A survey was faxed to 1313 Primary Care Physicians in Arkansas to determine the physician population currently treating and interested in treating patients with SCD. With a 13% response rate, 172 completed and returned the questionnaire. Results show that nearly 22.4% of respondents currently treat patients with SCD, and 34.3% have an interest in treating patients with SCD. Those interested provided their contact information for further interaction with the program (*see section on Long term Plans*). The map in Figure 2 shows the locality of the practice of physicians who indicated they were interested in treating patients with SCD. For comparison, additional maps are provided (Figures 3 and 4) showing possible locations of patients with SCD by looking at where insurance claims were filed and locations of newborns that screened positive for SCD.”

Figure 2: Where Survey Results show Interested Physicians Practice

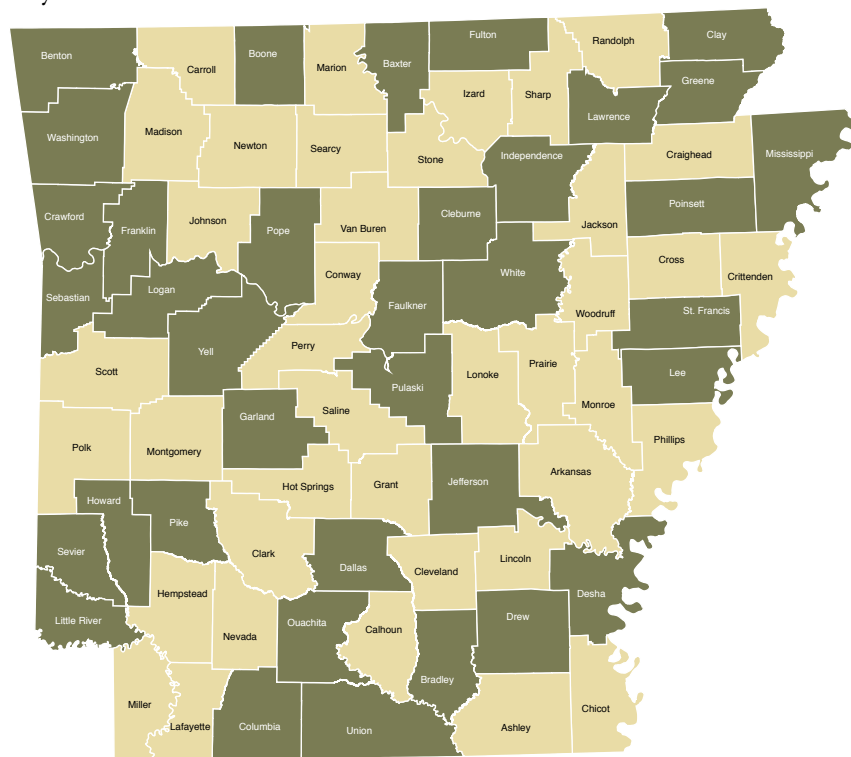
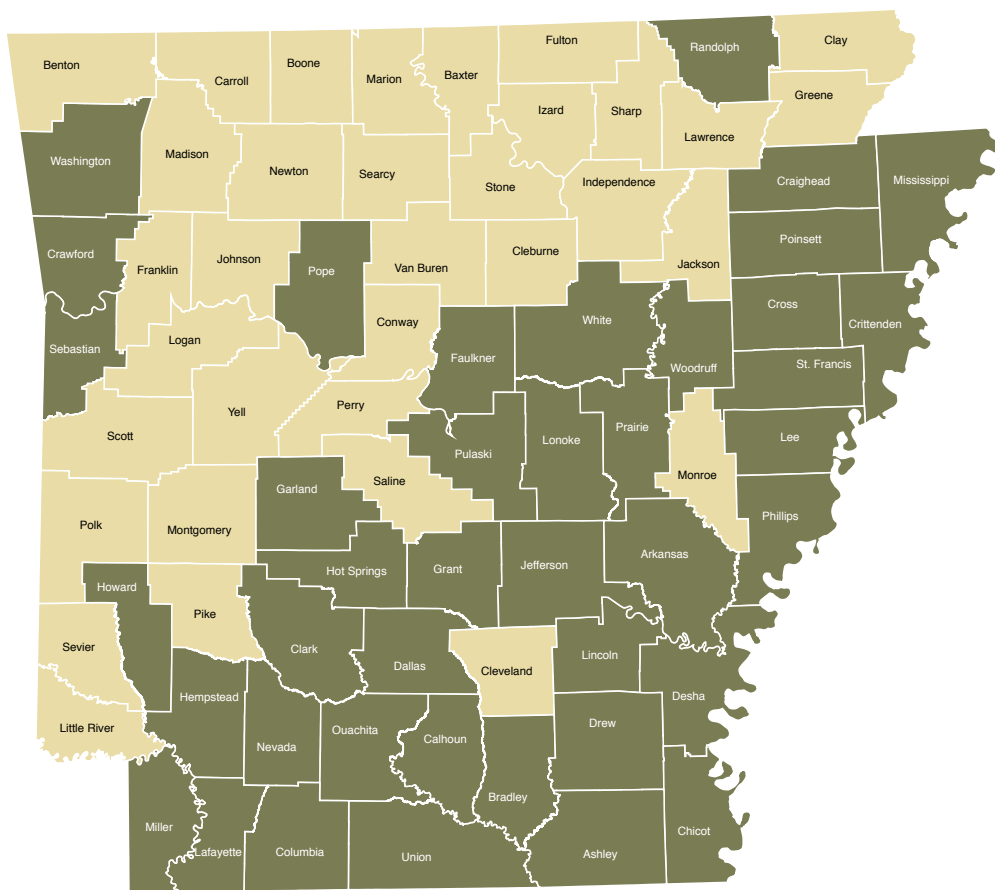


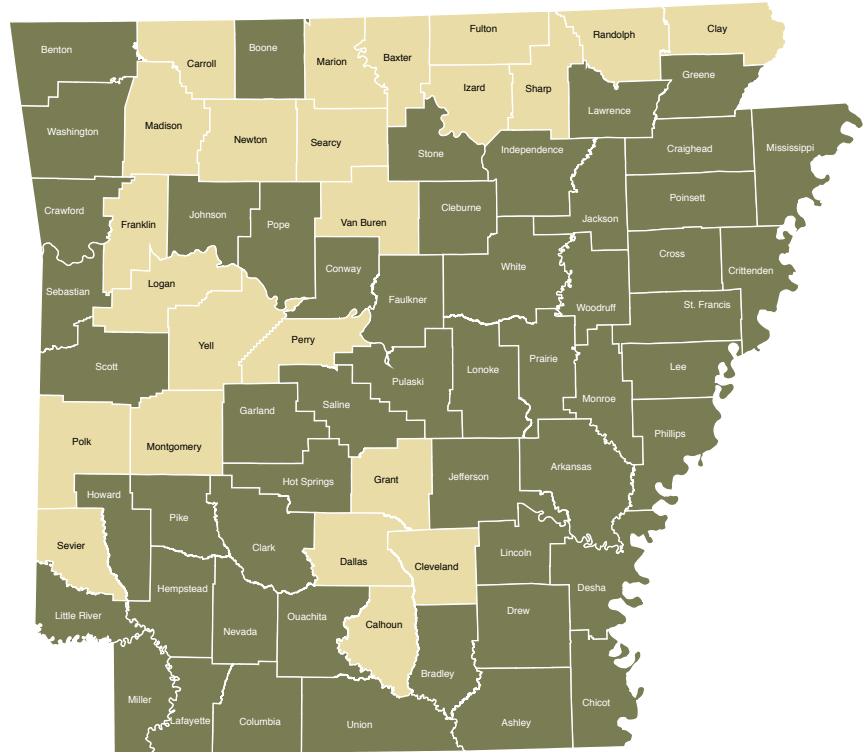
Figure 3: Counties with Infants with SCD
detected through Newborn Screening 1988-2009



Student Intern:

Another way the program conducts outreach is through the participation in the UALR master's level social work intern field program. UAMS Adult Sickle Cell Program works with a social work graduate student from UALR beginning in August and ending in May. The social work intern is an active participant in the interdisciplinary team. The intern begins by observing the medical team and social worker's role in the clinic and as the internship progress the intern takes on a more active role providing interventions to patients and family members. The intern also attends and participates in the monthly support group meetings. This partnership exposes not only the student intern to the world of sickle cell disease and minority health, but the student's entire graduate class through field work presentations the student gives to the class throughout the semester.

Figure 4: Counties Where SCD Patient Insurance Claims Filed (2008)





"As an adult I have been really blessed to not have a crisis in the last 30 years, but recently my blood counts dropped way below the average levels. I called the clinic, and was able to go check my levels at 6:30 am. By the time the results came back, the doctor and nurse were arriving to the office and called to tell me to come in for a blood transfusion. I hadn't received a transfusion in 30 years, so I was a little disappointed, but they talked me through it. They gave me the same care and attention I received when I use to attend the Sickel Cell Clinic at Arkansas Children's Hospital. That was really comforting."

Phyllis Dickerson
Patient

"I have had the opportunity to sit with other adult sickle cell disease individuals in a controlled environment with staff and registered nurses present to discuss physical difficulty and healthy lifestyles to help live a more productive life while living with the disease.

UAMS Adult Sickle Cell Program provides treatment and education that helps me both financially and physically. A program like this has been needed for such a long time and it's my goal to spread the word to other adults living with the disease that no longer do we have to suffer in silence for there is hope with UAMS Adult Sickle Cell Program."

Roy Wert
Patient
Conway County

Disease Registry

The Registry was approved in February 2015 and as of mid-June there were 41 patients enrolled. The registry contains health specific data on each patient, including information on their disease, family and health histories, treatments and disease complications. The registry also includes specimens (blood and urine) and an assessment of quality of life. There is currently no national sickle cell disease registry but the CDC is working towards the development of this in the future. Our aim is to be able to provide this registry data for inclusion in the national registry when this is initiated. The registry will provide us with more specific data on patients with sickle cell disease, provide us with knowledge on the specific disease burden in Arkansas and provide data for research to improve the disease treatment and outcomes.



"The hematologists' contribution is making a significant difference in our patients' care. The hematology fellows are now an integral part of the program. As the hematology section has grown and as more pure hematologists have joined our division, plans are being discussed to appoint a hematologist co-director with Dr. Devan to help move the program forward. The joint leadership will continue developing the program to meet its main mission of patient care, education and research. As of this year, four pure hematologists will be staffing the service, which will help maintain the quality of care and a healthy balance of different functions of the team members."

Issam Makhoul, M.D.

*Director, Hematology/Oncology Division
Internal Medicine Department*

What's next?

≡ **Expansion of clinic hours**

Our weekly half-day clinic is filling up quickly. We would like to add another half-day clinic to allow us to accommodate new patient appointments in a timelier manner. Our goal is to be able to see a new patient within 2 weeks of their request.

≡ **Database of community resources**

The goal is to create a statewide directory of community resources that provide assistance for housing, food, assistance with utility bills, and mental health providers. The directory would be organized by county and would be made available to patients in the Sickie Cell Clinic. The Social Worker creating the database will start with the counties of the highest sickle cell patients and continue to add counties until complete.

≡ **Development of patient advisory committee**

In developing a patient advisory committee our goal is to partner with our patients to improve the healthcare experience for all Sickie Cell

patients and their families. As part of this process, patients will be invited to share their points of view, perspectives, and experiences. Through their unique perspectives, they give input on issues that impact care, ensuring that the next patient or family member's journey is easier.

≡ **Create a State-wide Physician Network**

A compounding factor in the overall management of SCD is that many of the patients live rurally and do not have primary care providers managing their disease. We are looking to build a Sickie Cell Physicians Network across Arkansas in order for Sickie Cell patients to receive primary care close to home and visit the UAMS annually for the Adult Sickie Cell Multidisciplinary Clinic. With the surveys previously mentioned, we have identified Physicians that are interested in caring for this underserved population. We will be following up with these providers to discuss their interest, access their needs, and plan with them on how we can offer support.



To utilize the service of this program
call the 24/7 Call Center
@ 1-855-Sic-Cell (742-2355)
For more information visit
<http://sicklecell.uams.edu>