HANDOUT 1

UAMS Adult Sickle Cell Clinical Program:

A Year in Review

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A brief review about the disease…

Sickle Cell Disease is the most common hemoglobinopathy in the United States.

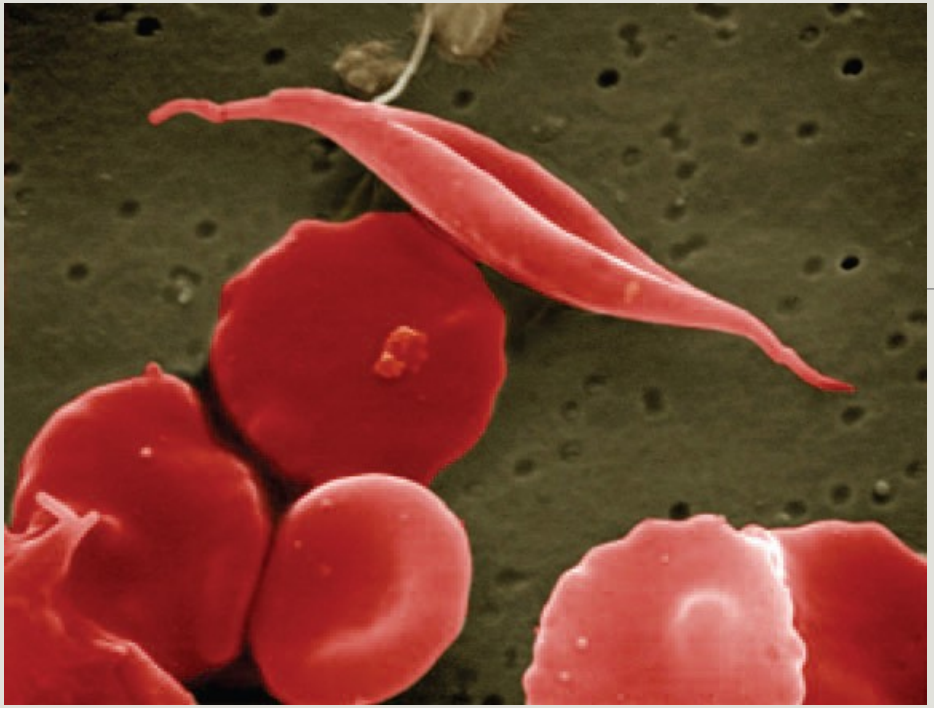
- Autosomal Recessive
- Wide spectrum of presentation: from sickle cell trait (Hb AS) which is largely asymptomatic, to Sickle cell anemia (Hb SS) which is the most severe form of the disease
- Vaso-occlusive phenomena and hemolysis are the hallmarks of the disease

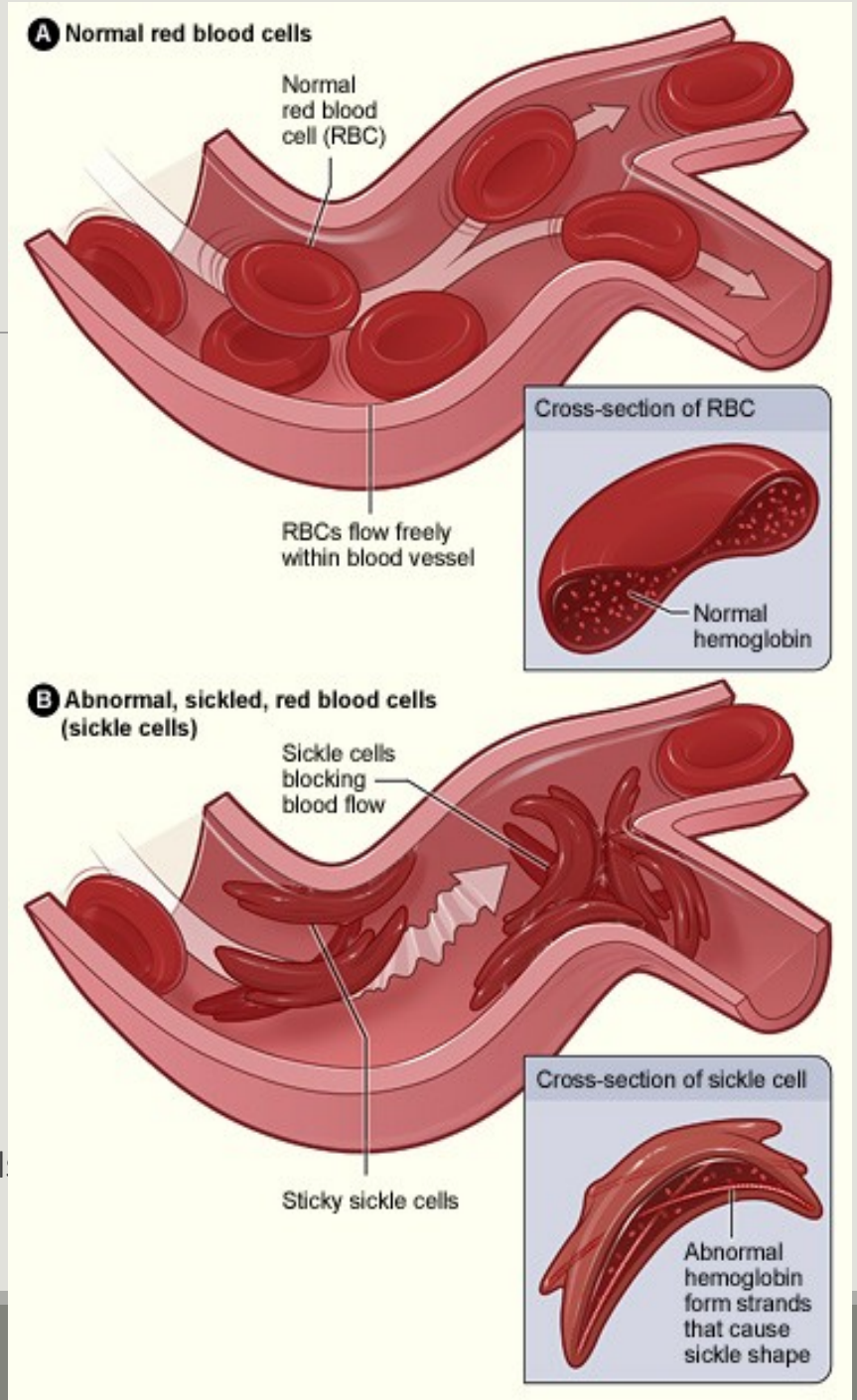
UAMS. ANGELS Antenatal and Neonatal Guidelines, Education and Learning System. Obstetrical Guidelines

Etiology

Sickle cell disease is caused by an abnormality in hemoglobin that results in the change in the shape and function of red blood cells.

- In people with sickle-shaped red blood cells, blood vessels can sometimes become clogged, preventing blood from flowing smoothly
- Hemoglobin is the protein in red blood cells that carries oxygen. So, people with abnormal hemoglobin (Hemoglobin S) have decreased oxygen-carrying capacity.





http://www.nhlbi.nih.gov/health/dci/Diseases/Sca/SCA_WhatI
.html

Who Gets this Disease?

In the United States, Sickle Cell Disease is most common among African and Hispanic Americans.

- The disease affects approximately 1 in 500 African Americans
- And 1 in 36,000 Hispanic Americans

Sickle Cell Disease is an Orphan Disease

Defined by the National Institutes of Health as a disease with a prevalence less than 200,000 people nation-wide.

- Actual numbers? Approximately 100,000 people in the United states with Sickle Cell anemia.

Incidence in Arkansas

Based on Newborn Screening, an average of 25 babies are born with Sickle Cell Disease every year in Arkansas.

- Newborn Screening has been going on in this state since 1988.

Prevalence in Arkansas

NOBODY KNOWS FOR SURE

Based on the newborn screening rate (25 per year), and the life expectancy of patients with the most severe form of the disease (42 for men and 48 for women), there could be at least 1,200 Arkansans with the disease.

At any given time, slightly over half of the total SCD population are of adult age.

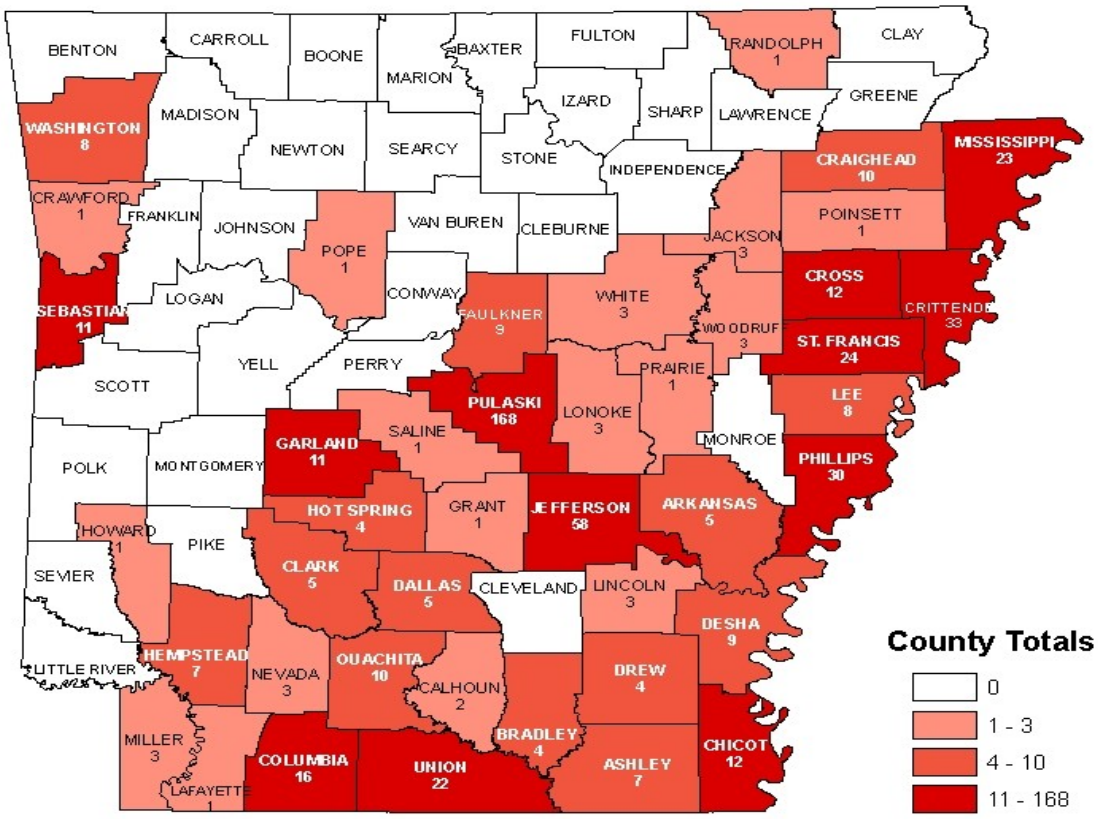
But what about people who move here?

What about people with less severe forms of the disease who can possibly live into their 60s?

So, Where are the patients with sickle cell disease?...

Total Infants with Sickle Disorders (S/S, S/C, S-β-thal) Detected through Newborn Screening

Arkansas,* October 1988 - September 2009 by County of Residence



*Includes Arkansas resident infants detected through adjoining states' newborn screening programs

UAMS Adult Sickle Cell Clinical Program Mission

UAMS will create an exemplary Adult Sickle Cell Clinical Program that will not only identify adults with the disease, but will also strive to decrease the burdens, both financial and physical, faced by Arkansas's adults with Sickle Cell Disease.

- Our goals:
  - Collect Data
  - Create a Clinical Program
  - Educate Patients, Families and Healthcare Providers
  - Evaluate the program

Data Collection

We received IRB approval to start a Disease Registry. There is no Nationwide Registry of Sickle Cell Patients yet.

So far, 60 patients have consented to enroll in the registry.

We are collecting

- Demographic information
- Healthcare utilization information
- Disease specific information
- Quality of life surveys
- Blood and Urine Samples

Plan to report de-identified data on a regular basis to the public regarding Sickle Cell in Arkansas.

Disease Registry

Voluntary

De-identified data

Goal: to enhance our knowledge of how this disease is impacting Arkansas.

Clinical Program

This is how we interface with our patients:

- Call Center
- Transition patients from AR Children's Hospital to adult care
- Multidisciplinary Clinic
- Inpatient Consult Service
- Infusion Room Appointments
- Apheresis appointments
- Patient Centered Monthly Meetings

Our clinic meets once a week, and patients are seen by a pain specialist, a hematologist, and APRN, RN, and Social Worker. When appropriate, we send our notes to the patients' primary care physician, with a plan of care recommended.

Call center

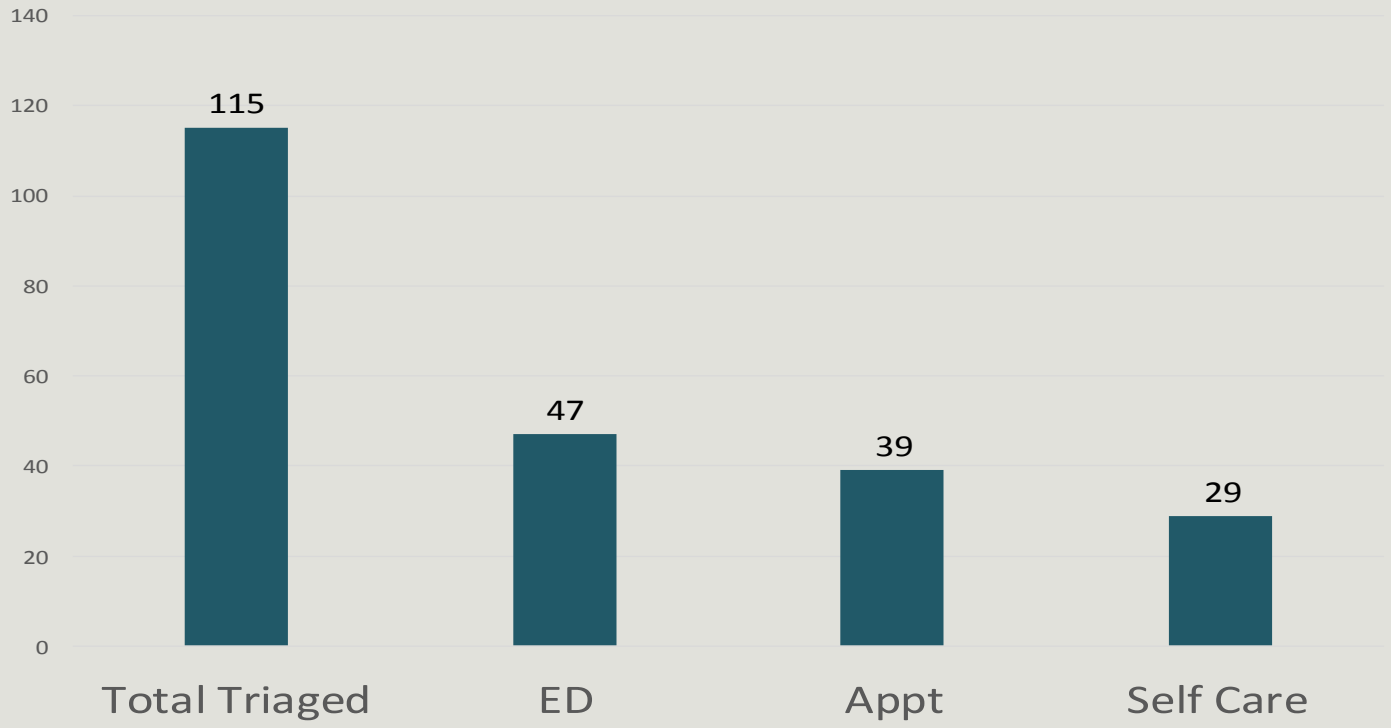
1-855-Sic-Cell (742-2355)

Patients and Providers can call any time of day or night with questions/concerns regarding sickle cell disease.

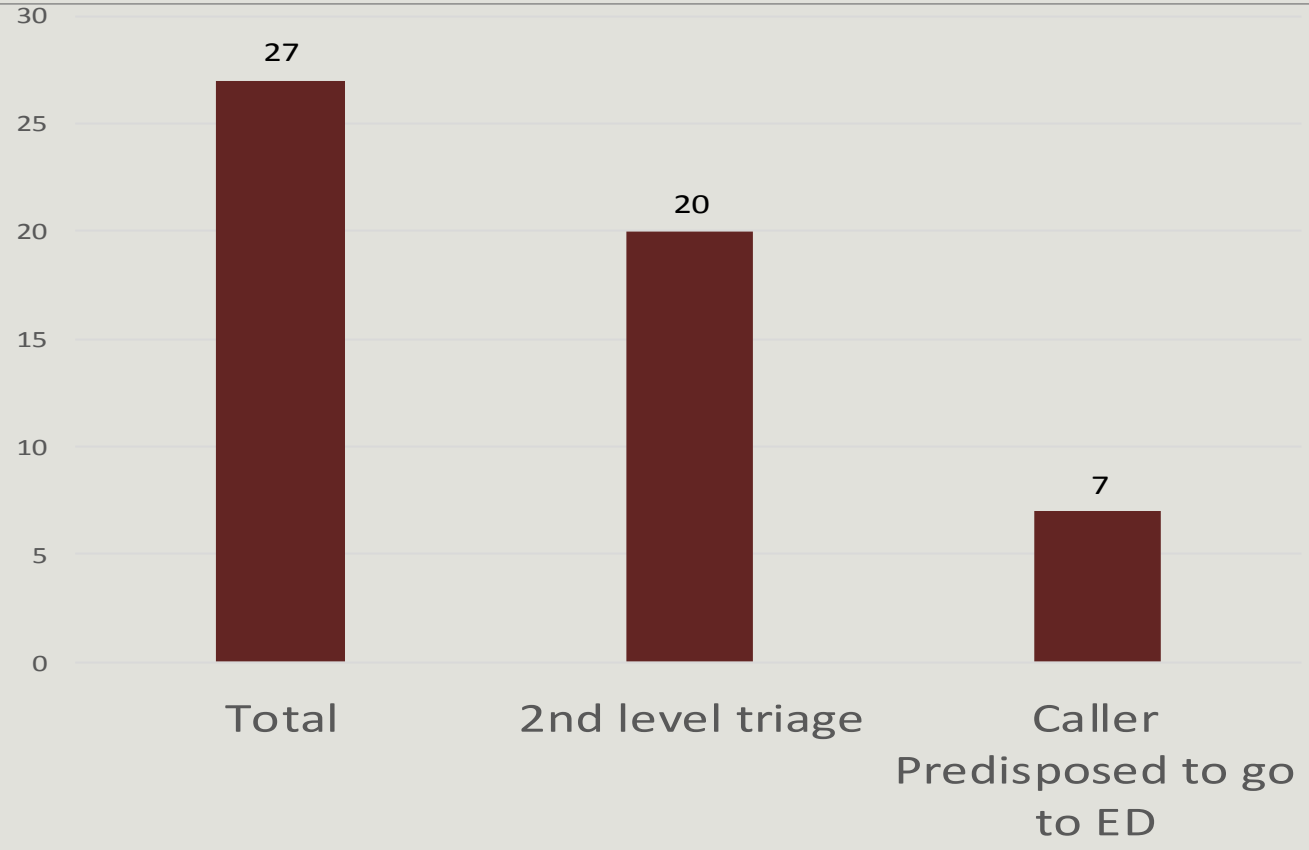
Nurses will triage the calls as necessary.

- Direct patient to the ED
- Link the outside physician with a doctor here to discuss the problem/possible transfer

Call Center—Triage Outcomes 2014



Avoided ED Visits



National Cost for Average Sickle Cell Patients

- Cost of ED Visit=$1572
- 68% of Pts 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 **27x1572=42,633**
- Potentially 68% of ED visits would have been admitted **68% of 27= 18**
- 18 potential admissions **18 x 21679= 390,222**
- **ED + Admissions= $432,855**

Transition Clinic

We work with the Sickle Cell Team at ACH to coordinate the care of patients transitioning from pediatric care to adult care

We help reinforce the patient/primary care relationship, and if that breaks down, we assist the patient in finding a new physician.

Social Worker is the point person for this aspect of the program.

Multidisciplinary Clinic

Wednesday Mornings

Winthrop P Rockefeller Cancer Institute

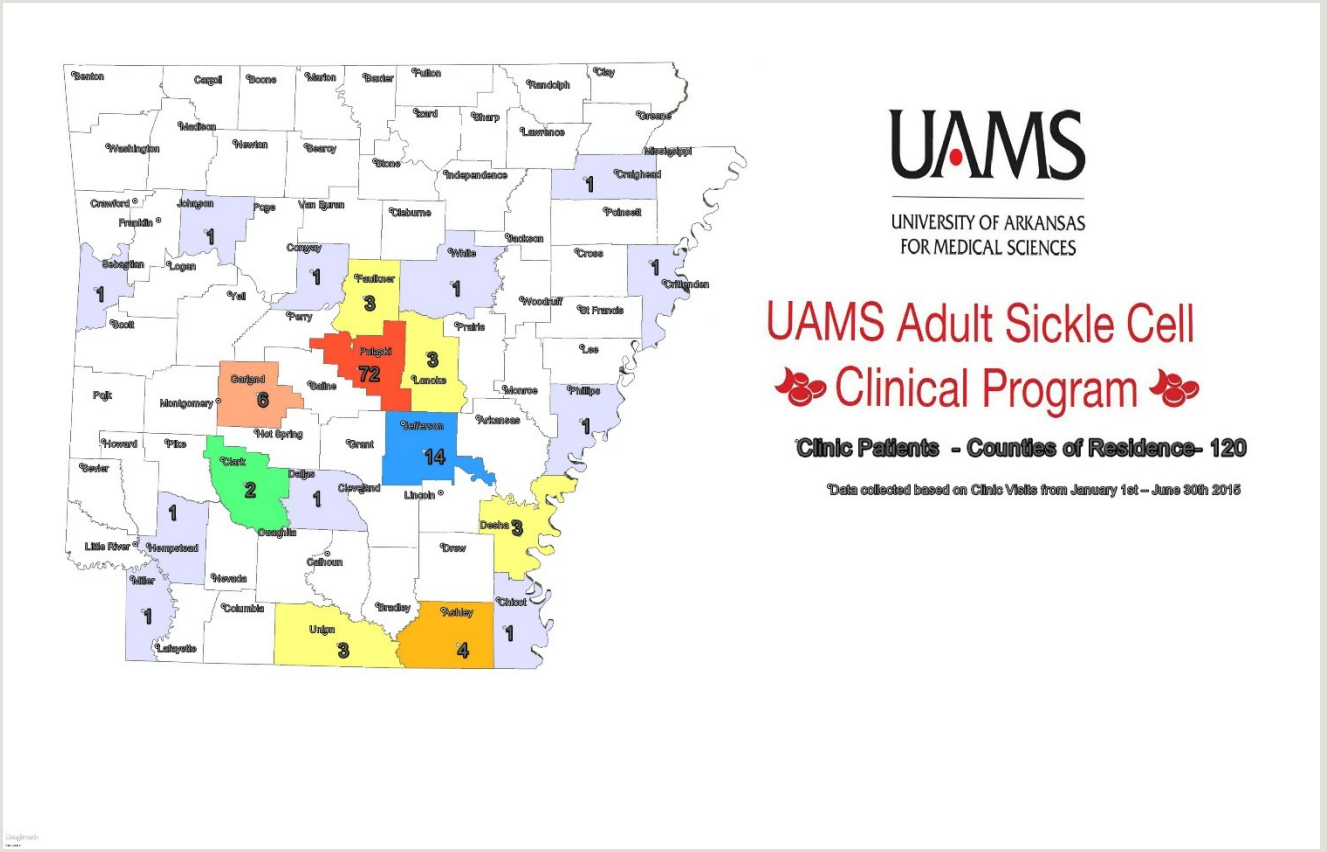
7th floor

Hematologist, Pain Specialist, APRN, RN and Social Worker. We often have a Lawyer present as well, to help with any legal issues that patients might have

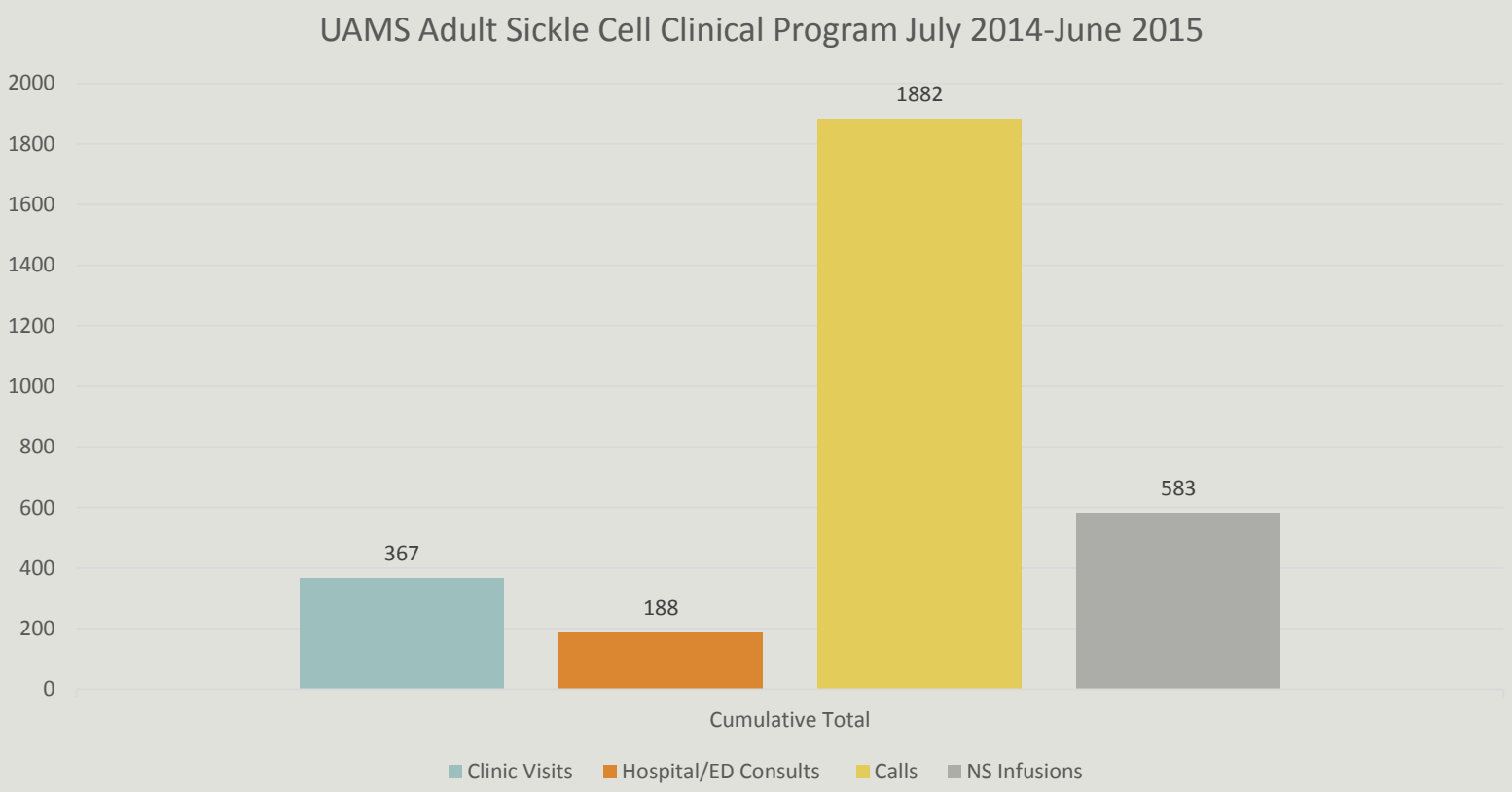
Goal is to compliment the care of the Primary Care provider – not to take over care.

- Pain contracts
- Yearly recommendations/plans of care

Who have we seen so far?



How have we seen them?



We have now contacted approximately 150 patients, through word of mouth, from transitioning from AR Children's Hospital, and from referrals from providers from all over the state.

We have a long way to go to reach all the adults with this disease.

If you know of patients that you'd like to refer, please call 1-855-Sic-Cell (742-2355).

Again, our goal is not to "take over" care, but to support your caring for these patients, in whatever ways are useful to you.

Inpatient Consult Service

APN, SW and physician see inpatients with the disease

- Assist with pain control
- Write pain medication prescriptions on discharge, if necessary
- Make disease-specific recommendations
- Assist with disposition
- Arrange Follow up in Sickle Cell clinic

  Available Mon-Fri during business hours. If consult is placed at night or on the weekend, hem/onc fellows are on call to assist.

Patient-Centered Meetings

RN and LCSW organize the meetings

3rd Monday of every month

Downtown Library, 6pm

Guest Speakers

Patients come together outside of the hospital setting to discuss topics of interest to them.

Education

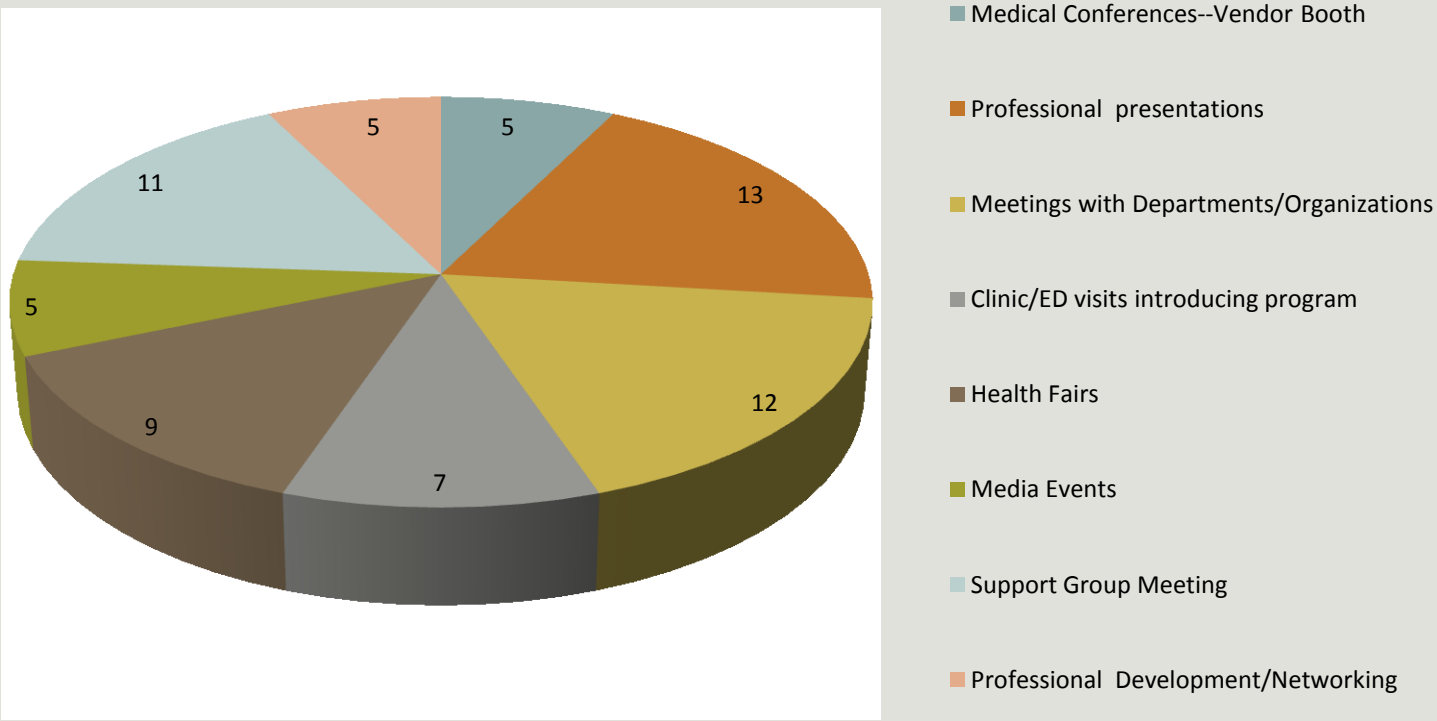
We created Treatment Guidelines (available on our WebSite – http://sicklecell.uams.edu) to assist healthcare providers on best care practices regarding treating this rare illness.

We give lectures like this one quarterly, on educational topics related to Sickle Cell Disease.

We go to health fairs, and other events as invited… and are happy to come to your community, to talk to physicians, APNs, RNs, Social workers about this rare disease.

We are creating “Learn On Demand” modules for our patients to take online, to learn more about aspects of the disease.

Outreach, FY 2014-2015



Teleconferencing

Quarterly presentations/case studies

Interactive

Goal: to build relationships with primary care providers around the state, who are interested in taking care of patients with this rare disease. To give them a forum for education and discussion about disease-related issues.

New National Guidelines Published in the last year

http://www.nhlbi.nih.gov/guidelines

161 pages of the latest guidelines for “Evidence-Based Management of Sickle Cell Disease”

An Expert Panel Report, 2014

New Medication

There is now an oral iron chelator that is does not have to be dissolved in liquid.

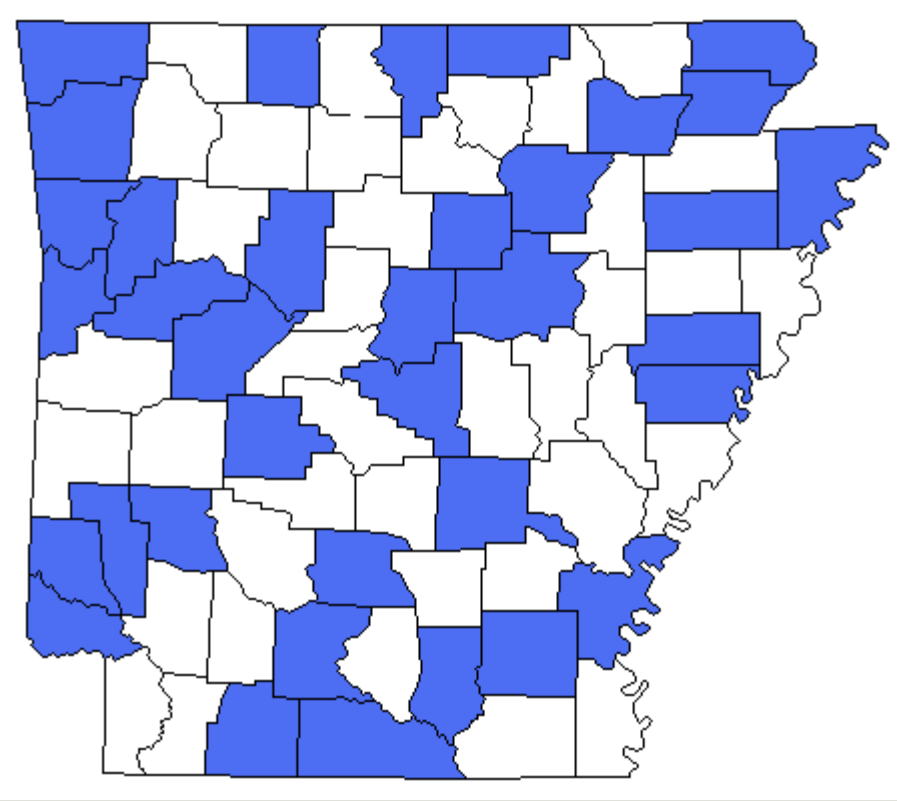
Jadenu is the pill form of deferasirox.

Research Efforts

A graduate student conducted a survey for our team. He asked physicians all over the state if they take care of patients with Sickle Cell disease. He also asked them if they were interested in doing so.

He organized the results, and we hope to capitalize on his efforts.

Where interested physicians practice…



The future…

We've identified physicians who are already taking care of patients with this disease, or who are interested in doing so. Now we need to take the next step.

Plan to have quarterly teleconference meetings with those providers, presenting case studies, and collaborating in caring for these complex patients

My dream: to identify a core group of 50 physicians across Arkansas, willing to care for 10-20 adults with sickle cell disease. We could work closely with them to care for these patients, meet quarterly to discuss ***and standardize*** that care.

- Those 50 physicians could see the 20 patients 4-6 times per year (2nd Tuesday of every other month, for example).
- They would collaborate with a local Social Service agency that might go to the clinic that day as well
- We could be available by Teleconference on that day, too, to offer support and recommendations for care.
- We could try to secure grant funds to compensate the physician and the social service agency for their efforts
- Thoughts?

Clinic Expansion…

We saw 367 clinic patients last week, and only have clinic ½ day per week. This means we averaged 7 patients at every clinic.

These are “high needs” patients, and to see 7 in 4 hours is difficult.

We will be discussing adding another half day per week in the near future. But we currently share our clinic space, and time (and space) are rare commodities.

Bricks and Mortar…

We'd love to have a designated building that could house…

- Our clinic
- Some infusion/apheresis stations
- Conference/Education room
- Consultant's Rooms
- Our staff

- If patients could come there any time they needed (within business hours), I think we could decrease the number of admissions even more. Other states are running "day hospitals," where patients can come, get fluids and pain meds if necessary, and even transfusions… then go home that night.

Evaluation

We plan to evaluate our program's effectiveness with our patients yearly, via a phone survey.

Another marker of patient satisfaction is attendance at the patient-centered monthly meetings.

We plan to develop an Advisory Committee, made up of patients, physicians, nurses, that meet quarterly to discuss issues relevant to patient care, and to plan for the future.

Staff

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Thank you!

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http://sicklecell.uams.edu

1-855-Sic-Cell (742-2355)