

Revised Recommendations October 2015

1. Arkansas needs a Comprehensive Sickle Cell Program, in which children and adults can receive state of the art care and case management, regardless of where they live.
2. The Hubs would provide a comprehensive, multidisciplinary network; all patients involved would have at least one yearly comprehensive visit. Each visit would result in the development of a patient specific plan of care, which would be maintained by the center, the patient, and the patient's "Spoke" site. The comprehensive centers would be staffed by medical directors, and advanced practice nurses (APN) or nurse practitioners with specialized knowledge and/or experience in sickle cell disease, appropriate administrative and support staff; and would have available other services which are important in the care and management of sickle cell disease, such as pain management, social work, vocational training/support, etc. The Hubs will also develop a "24/7" call system, whereby patients, "Spoke" sites, or other medical professionals throughout the state can obtain immediate advice regarding the care of patients with sickle cell disease from trained personnel.
3. The "Spokes" would be located in areas of the state with high concentrations of sickle cell patients, and would be available for interim management of acute complications of the disease, such as painful crises and infections. Spokes would be staffed by a willing physician provider as well as a designated sickle cell nurse, and would implement the patient specific plan of care, with appropriate backup from the Hub as needed.
4. The state Medicaid office should be involved in the implementation of some or all of this plan, in that some revisions ("waivers") of the Medicaid program, specifically those limiting outpatient care and lab, and those limiting the number or prescriptions per month, are detrimental to the ability to deliver appropriate comprehensive preventive care to sickle cell patients. Additionally, aggressive, comprehensive case management of sickle cell patients, both children and adults, would result in not only improved care and quality of life for the patients, but also, based on the experience in other states, lead to significant potential for cost savings.
5. A sickle cell disease educational outreach coordinator should be hired to help the agencies that provide educational services integrate their activities, and to address unmet training needs.