

Approved February 8, 2016

EXHIBIT C

STAFF NOTES

LEGISLATIVE TASK FORCE ON SICKLE CELL DISEASE

Monday, October 5, 2015

10:30 a.m.

**Room 272, State Capitol
Little Rock, Arkansas**

The Legislative Task Force on Sickle Cell Disease met Monday, October 5, 2015, in Room 138, State Capitol, Little Rock, Arkansas. The following members attended: Representative Robin Lundstrum, Ms. Angela Mull, Ms. Michelle Murtha, Ms. Patricia Purifoy, and Dr. Michelle Smith.

Opening Remarks by Representative Robin Lundstrum

Representative Lundstrum called the meeting to order.

Staff Notes of September 2, 2015 Meeting [Exhibit C]

The minutes of the Task Force on Sickle Cell Disease were reviewed for informational purposes.

Sickle Cell Clinic Update

Dr. Robin Devan, Assistant Professor, Internal Medicine, University of Arkansas for Medical Sciences (UAMS), submitted a PowerPoint entitled, "UAMS Adult Sickle Cell Clinical Program Year End Review". Dr. Devan described what Sickle Cell Disease is and the characteristics of a sickled cell. UAMS Sickle Cell Clinic currently meets all four goals of educating patients, families and health care providers, data collection, creating a clinical program, and evaluation of the Sickle Cell Clinical Program. There currently is not a nationwide registry for sickle cell; however, there is currently a statewide registry that collects demographic data, health care specific data, blood and urine samples and quality of life surveys.

The Sickle Cell Clinical Program includes:

- A call center
- Transition Clinic (from pediatrics to adult clinic)
- Multidisciplinary clinic
- Inpatient consult services at UAMS
- Infusion room appointments (receive saline and pain medication)
- Patient centered monthly meetings at Central Arkansas Library

Dr. Devan aspires to create a patient teleconference, partner with physicians across the state and ask them to commit to 10-20 patients, increase clinic services to an additional half day of operations, create a physical space dedicated to serve as the UAMS Sickle Cell Clinic, improve patient evaluations, and create an advisory committee comprised of patient, staff, doctors and nurses. The sickle cell clinic currently offers teleconference for providers to gain additional information.

Funding for Youth Transitioning from Pediatric Care to Adult Services

Dr. William Golden, Medical Director, Arkansas Medicaid, UAMS Professor of Medicine and Public Health, explained that Arkansas Medicaid currently invests in treatment and therapy of Sickle Cell Disease through the Angels Program. UAMS currently provides robust care for pediatric patients. Dr. Golden went on to explain that statistics reflect an adequate amount of available benefit. Statistics show that patients do not use all of the benefits available and they also do not fall short of their medication list; no one has required an expansion of benefits. UAMS is actively working to improve the transition from pediatric clinic to the adult clinic. Medicaid expansion has reduced the uninsured rate by 50% and sickle cell patients have greatly benefited.

Educational Initiatives for Students with Disabilities

Dr. Brett Powell, Director, Arkansas Department of Higher Education (ADHE), stated that compliance is a grey area with ADHE due to duties outlined in governing legislation. ADHE is better served as a role of communication between colleges and universities. Dr. Powell stated that ADHE would be a great source of collecting and disseminating information regarding sickle cell. Each campus is required, by federal law, to have an Americans with Disabilities Act Coordinator (ADA) in the disability resource office. ADA compliance requires each campus to follow the federal definition of “disability”. Ms. Angela Mull explained that while Sickle Cell Disease is not listed as a “disability”, it does have debilitating symptoms. Some campuses offer testing for Sickle Cell Disease.

Additional Concerns

The members of the Work Group on Sickle Cell Disease expressed a desire to create goals and objectives to define future efforts. The work group would also like to add representation from the UAMS Sickle Cell Clinic to the work group.

There being no further business, the meeting adjourned at 12:00 p.m.