EXHIBIT E-2

MINUTES

LEGISLATIVE TASK FORCE ON SICKLE CELL DISEASE
Wednesday, September 8, 2010
1:30 p.m.
Room 207, State Capitol
Little Rock, Arkansas

The Legislative Task Force on Sickle Cell Disease met Wednesday, September 8, 2010, in Room 207 of the State Capitol in Little Rock, Arkansas. The following members attended: Mr. Germaine Johnson, Chair; David Deere, Dr. Jocelyn Elders, Idonia Trotter, and Dr. Bob West.

Dr. Becton joined the meeting at approximately 2:28 p.m. via conference call.

Legislators attending: Senator David Wyatt; Representatives Billy Gaskill, Jim Nickels, and David Rainey

Also attending: Mr. Gene Gessow, Dr. William Golden, Cindy Brown, and Sheena Olson

Mr. Deere called the meeting to order and recognized the Task Force members and guests for introductions.

Comments by Representative Rainey
Representative Rainey gave a brief overview of Act 1191 of 2009 that created the Legislative Task Force on Sickle Cell Disease, noting the Task Force (TF) will need Mr. Gessow and Dr. Golden's assistance and guidance in terms of putting a program in place that will support sickle cell treatment. [Attachment #1]

The TF will provide Mr. Gessow and Dr. Golden a copy of Dr. Smith's Sickle Cell Disease Consultant's Recommendation, *Arkansas's Best Options for Creating an Adult Sickle Cell Disease Clinical Program,* TFs final report, and recommendations.

Overview of Sickle Cell Impact of Medicaid Limits on Adults with Sickle Cell Disease
[Attachments #2 & #3]

Dr. Elders read an email submitted by Dr. Baltz [Attachment #4] describing Medicaid benefits for sickle cell patients. Medicaid's current benefits for sickle cell patients allows for only 12 physician visits per fiscal year and 12 outpatient hospital visits per fiscal year with a total lab and x-ray benefit of only $500 per year. These benefits make no provision for sickle cell crises, the most costly aspect of sickle cell care. The bottom line is that sickle cell patients have difficulty accessing medical care due to lack of adequate allowable visits under the current Medicaid guidelines. If primary care physicians and hematologists are not paid to see the patients in the office, then the patients are seen in the ER.

The TF has to find a way to provide more services to sickle cell patients to reduce pain crises cost and ER visits. Extending the benefits or reclassifying them would greatly benefit patients and Medicaid. This can be accomplished through a Medicaid waiver. Dr. Elders stressed the importance of educating new doctors regarding sickle cell disease.

Representative Gaskill requested more information pertaining to the sickle cell disease. Dr. Elders will gather this information and forward it to the staff to pass on to Representative Gaskill.

Mr. Johnson recognized the following representatives from the Medical Services Division, DHS: Mr. Gene Gessow, Director, Medical Division; Dr. William Golden, Medical Director, Health Policy; and Ms. Sheena Olsen, Chief Program Administrator, Medical Assistance.

Mr. Gessow sated he will review the Medicaid restrictions and examine the issues surrounding sickle cell disease. He will work with the Department of Health to determine a way to work around the restrictions. He feels that the current restrictions can be changed without a Medicaid waiver. However, legislation and/or state plan changes are necessary before any changes can be implemented. Medicaid is careful in trying not to discriminate among diseases. At times, Medicaid has looked at specific diseases for waivers such as

tuberculosis, breast and cervical cancer, and HIV-AIDS. Mr. Gessow will look at ways to accomplish removing Medicaid restrictions for sickle cell patients. This has to be done in a way that is consistent with Medicaid's general policy as opposed to the needs of a specific population.

Representative Gaskill suggested the TF have the Medicaid staff address sickle cell disease issues during a Public Health Committee meeting. This will help to inform other legislators who may be unaware of this issue. Mr. Gessow asked that the TF call them as witnesses to testify when the final report is presented to the Public Health Committee.

Mr. Deere said the adult sickle cell crisis is substantial in Arkansas noting the TF has investigated all of the sickle cell disease issues relating to children and adults. Ms. Trotter said Arkansas is doing a good job taking care of its sickle cell youth patients but, once they reach the adult age, they fall off the map.

Overview of Sickle Cell Disease and the Need for Services in Arkansas [Handout #1]
Mr. Deere gave an overview of sickle cell disease. In Arkansas, sickle cell disease affects more than 1,000 individuals. Taking care of these patients places a huge burden on the health care system. A lot of the care provided is not reimbursed and a substantial number of patients do not have insurance.

According to a University of Florida study, the average monthly cost of providing health care to an individual with sickle cell disease is $1,946. The highest costs were for individuals age 30 to 39 and averaged $34,266 yearly. Some states that have initiated an aggressive sickle cell program have seen significant savings.

Many adults with sickle cell disease lack access to a knowledgeable physician who can treat them. This causes unnecessary visits to the ER and hospitalizations. There is a great need to expand knowledge about sickle cell disease among health professionals to develop more clinical options for care and to change current reimbursement policies relative to sickle cell.

Some Arkansas physicians said that one of the biggest barriers that prevent physicians from treating sickle cell patients were the limitations on Medicaid coverage. Medicaid's role involves helping to develop possible solutions to resolve this issue.

In response to a question by Representative Gaskill, Dr. Golden said sickle cell disease is first diagnosed at birth. However, there are unfortunate situations where sickle cell disease is often read as Sickle Cell (SC). Another disease is the Sickle Cell (SC) hemoglobin disease which is a cousin of sickle cell but not as severe. Patients with SC can interchange and have a misdiagnosis. This is a significant problem in Arkansas.

Dr. Golden asked how many Arkansas sickle cell patients have no health insurance or Medicaid coverage. Mr. Deere could not provide a definite answer due to poor data. However, the majority of individuals with sickle cell disease are uninsured. This could possibly change when health care reform goes into effect. He predicted this group of individuals may be included under the Medicaid expansion. Dr. Golden said that information based on claims data for sickle cell disease is probably 30% too high.

Dr. Elders stressed the importance of educating new doctors regarding sickle cell disease.

Comments by Chairman Johnson
Mr. Johnson said that living with sickle cell disease affects him on a daily basis. He discussed how sickle cell pain crises affect him and other patients. He described a situation where a patient was having a pain crisis and had to wait for hours at the hospital before being seen by a physician This was due to the patient's insurance coverage.

Mr. Johnson made passionate remarks regarding others affected by the disease. He said doctors are not reimbursed for services they provide, noting they "eat the cost" without being reimbursed. Sickle cell patients are dying; therefore, the vitality of these patients depend on Medicaid changing its restriction policy.

Dr. Becton said the key issues regarding Medicaid's insurance coverage for patients with sickle cell disease include removing Medicaid restrictions on the number of visits per month and the number of prescriptions per month. Of importance to the sickle cell patient population is minimizing or preventing the types of episodes

that lead to hospital admissions, such as pain crises and infections. This can be done through ambulatory care. Hydroxyurea is the most valuable drug in treating sickle cell disease patients.

In response to a question by Dr. Golden, Dr. Becton said hydroxyurea and vitamins are crucial medications that sickle cell patients use, noting that one oral medication is used when a painful crisis occurs. Sometimes short-term and long acting medications may be required. Patients requiring blood transfusions need Exjade, a oral pain medication. It is difficult to treat sickle cell patients with other core-morbidities like high blood pressure, diabetes, and other medical problems.

Mr. Gessow said the claims database is an imperfect way to identity the health status of sickle cell patients. He is looking for markers that can be used to identify an accurate number of sickle cell patients and their medications. He asked if there are other markers that can be considered on a claims form that would identify a primary diagnosis.

In response to a question by Mr. Gessow, Dr. Golden said he feels that all of the sickle cell disease patients are identified.

Senator David Wyatt asked the TF to present all of the necessary information to the legislature. He said "bring everything you need and we will run with it".

Dr. Elders thanked the guests for attending the meeting.

There being no further business, the meeting adjourned at 2:46 p.m.