

MINUTES**LEGISLATIVE TASK FORCE ON SICKLE CELL DISEASE****Tuesday, July 17, 2012****10:30 a.m.****Room 272, State Capitol****Little Rock, Arkansas**

The Legislative Task Force on Sickle Cell Disease met Tuesday, July 17, 2012, in Room 272 at the State Capitol in Little Rock, Arkansas. The following members attended: Mr. David Deere, Mr. Germaine Johnson, Dr. Michelle Smith, Mr. David Rainey and Dr. Suzanne Saccente.

Also attending: Senators Joyce Elliott and Linda Pondexter-Chesterfield

Opening Remarks by Senator Joyce Elliott

Senator Joyce Elliott, sponsor of Act 1149 of 2011, called the meeting to order and recognized Task Force members for introductions. Each member introduced themselves and briefly explained their occupation. Senator Chesterfield was recognized for comments. She stated she was very interested in the sickle cell disease noting that the Hospital and Medicaid Subcommittee, in which she is the chairperson, will have to oversee and do a lot of work with the Affordable Healthcare Act (AHA) to prepare the legislators for the upcoming legislative session. The Subcommittee will meet on August 14 and August 15, 2012, to learn everything that is pertinent as to how the Department of Human Services (DHS) operates, and to have discussions that are meaningful, thoughtful and relevant to the AHA. She encouraged the Task Force to consider appointing someone to attend these meetings.

Senator Elliott recognized Ms. Robin Lockhart, University of Arkansas Medical Science (UAMS), for comments. Ms. Lockhart stated that she works with Mr. David Deere at UAMS. She also appreciates the hard work that everyone has given.

Senator Elliott's role with the Task Force is to assist with the organization and startup process. The Task Force agreed to postpone approving the September 7, 2010, and September 8, 2012 meeting minutes until the next committee meeting. Senator Elliott encouraged the members to read the legislation that created the Task Force.

Discuss Task Force Officers

The Task Force had a lengthy discussion regarding the appointments. The Task Force is required to elect a chair and vice-chair at the next committee meeting.

Set Task Force Meeting Calendar

Senator Elliott suggested that the Task Force decide on a meeting schedule. After a brief discussion, **the Task Force agreed to meet the first Wednesday of each month.** Therefore, the next scheduled Task Force meeting date will be held on Wednesday, August 1, 2012, at 10:30 a.m. Agenda items will include: revising goals, electing officers, and approving minutes.

Discuss Task Force Goals and Objectives

Mr. Rainey stated that the Task Force incorporated a number of recommendations into its final report. After serious deliberations, research, and consultations, the Task Force identified priorities related to the report. Mr. Rainey suggested that the Task Force reference the report as a starting point as to what should come next. Mr. Deere stated that among those recommendations, **the Task Force agreed that the number one priority is to establish an adult sickle cell clinic.** Senator Elliott requested that a copy of the final report be sent to the Task Force members for review.

Upon request by Senator Elliott, Mr. Deere explained that the legislature identified UAMS as the facility for establishing the adult sickle cell clinic. Currently, Arkansas Children's Hospital has an excellent sickle cell clinic for children, in which Dr. Saccente oversees and represents, but adult sickle cell patients do not have a facility of a similar nature to serve them. Mr. Deere stated that currently adult sickle cell patients are forced to find care wherever they can. Mr. Johnson informed the committee that UAMS had received most of the funds to begin establishing the adult sickle cell

clinic noting that he is waiting to hear back from UAMS to set up a meeting time to discuss whatever is needed for establishing the adult clinic.

Senator Elliott asked for clarification regarding the legislation that was sponsored by Representative Reginald Murdoch during the previous legislative session, the Task Forces' vision of the adult sickle cell clinic, and where the gap is. Mr. Johnson replied that \$350,000 has been allocated to establish the adult sickle cell clinic noting that \$100,000 of this amount would be distributed over three years. He stressed the importance of additional funds needed to operate the clinic once it's up and running. Mr. Rainey added that in the beginning, the adult sickle cell clinic was intended to be established as a "hub and spoke". The organizational service delivery would serve as the "hub" and what remains would be the additional funding needed for the "spoke" that would be outsourced to regional centers placed in areas where there are high incidences of the sickle cell disease.

In response to a question by Senator Elliott regarding whether the "hub" and "spoke" is part of the Task Force goals or legislation, Mr. Deere replied that he believes that the "hub" and "spoke" was part of the Task Force recommendations noting that the central unit would provide resources to the regional centers. Mr. Deere stated that the legislation scaled back to establishing the adult sickle cell disease clinic at UAMS. He noted that the Task Force cannot lose sight of establishing resource centers. **Senator Elliott suggested that the Task Force think about additional legislation to establish regional centers and a recurrent funding stream.** She stressed the importance of the Task Force having conversations with legislators regarding this issue.

Regarding the funding for the adult sickle cell clinic, Mr. Deere stated that one thing that is going to have a huge impact on the financial viability of it is whether or not the state decides to do the Medicaid expansion. He noted that unreimbursed care is one of the biggest problems for sickle cell programs around the country. If the state does not participate in the expansion it would probably continue to have a lot of unreimbursed care that would affect the financial viability of the clinic and the ongoing funding needs. **Mr. Johnson stated that doctors are turning away adult sickle cell disease patients due to unreimbursed care. He noted that this issue should be one of the top priorities for the Task Force to deal with.** Senator Elliott stated that issue would be a great topic of discussion at the August 14th and August 15th meetings.

Senator Elliott asked for an explanation regarding the problems with the Medicaid Waiver. Mr. Johnson replied that the Medicaid Waiver would allow payments for more than four medications per month, six hospital days per year and reimbursements. This should result in a better outcome for the patients. The state Medicaid office should be involved in implementation of either the entire plan or part of the plan. Some provisions/waivers of the Medicaid program specifically, those limiting outpatient care and lab, and those limiting the number of prescriptions per month, are detrimental to the ability to deliver appropriate comprehensive preventive care to sickle cell patients.

Senator Elliott is interested in learning more about the history of the Medicaid Waiver and who is responsible for putting the rules in place in order to get it changed. She requested information on what other disease(s) are treated in a comparable fashion or non-comparable fashion. Mr. Deere stated that the Medicaid Waiver limits are the state standard limits for Medicaid. Dr. Suzanne Saccente stated that the prescription numbers conforms to Medicaid rules for all diseases.

Senator Elliott stated that upon request by the Task Force, she would invite someone to speak to the Task Force about the Medicaid Waiver procedure, and request someone from the DHS to present the results of the evidence-based process. Mr. Rainey stated that the Task Force could not get DHS on board with approving a Medicaid Waiver recommendation for the sickle cell disease; the Medicaid Waiver was not included in the Task Forces' final report. Mr. Rainey noted that the Task Force was successful with getting individuals to listen to them when they revealed the state and medical systems would save money without increasing any costs if the Medicaid Waiver was implemented for sickle cell disease patients.

Mr. Johnson stated that the previous Task Force discussed creating a sickle cell registry to determine how many patients were in the state. Dr. Saccente stated that good data is available on the number of newborn sickle cell patients that are diagnosed each year, but of those numbers they do not know how many patients have moved out of state, those that are having complications or that have died. Senator Elliott asked if the data includes the number of newborns with the sickle cell disease trait. Dr. Saccente replied that Dr. Bob West has access to this information.

After a brief discussion regarding individuals that have been diagnosed with the sickle cell disease trait, Senator Elliott asked would it be cumbersome to have this information included on the vaccination records. Dr. Michelle Smith stated that after discussing this issue with Dr. West, they feel that it would be a good recommendation from the Task Force to track individuals that are diagnosed with the sickle cell disease upon birth. She noted that legislative action may be required to include the sickle cell trait information on the vaccination records.

Mr. Deere stated that Dr. West had developed a budget proposal for establishing a registry, maintaining it, and tracking the individuals. **Senator Elliott stated that it would be a good idea to get colleges to do sickle cell screenings.** Mr. Deere stated that the National Collegiate Athletic Association has mandated all Division I universities to test their athletes for the sickle cell disease trait.

Announcements

September is Sickle Cell Awareness. Sickle Cell Fun Day will be held at the University of Arkansas at Little Rock.

There being no further business, the meeting adjourned at 11:45 a.m.