

MINUTES**LEGISLATIVE TASK FORCE ON SICKLE CELL DISEASE****Tuesday, September 7, 2010****12:00 p.m.****Room 207, State Capitol****Little Rock, Arkansas**

The Legislative Task Force on Sickle Cell Disease met Tuesday, September 7, 2010, in Room 207 of the State Capitol in Little Rock, Arkansas. The following members attended: Mr. Germaine Johnson, Chair; Mr. David Deere, Dr. Jocelyn Elders, Ms. Kimberly Hayman, Ms. Christine Patterson, and Ms. Idonia Trotter

Also attending: Representative David Rainey, Hanan Givens, and Heather Dunlap

Mr. Johnson called the meeting to order.

Consideration to adopt Minutes of August 26, 2010 (Exhibit C)

Ms. Patterson made the motion to approve the minutes. The motion was seconded by Dr. Elders and approved.

Medicaid Waiver

Mr. Deere said that obtaining a Medicaid waiver is difficult and time consuming and will require local approval for administering. Mr. Deere estimated that a waiver could not be granted prior to March, 2012, at the earliest. However, if the current plan is amended, the process may be quicker. Representative Rainey stressed the importance of identifying individuals who can expedite this process.

Representative Rainey scheduled a meeting with the Department of Human Services Medicaid Director, Mr. Gene Gessow and Medical Director, Dr. William Golden. He asked if the Task Force (TF) would be available to attend this meeting on Thursday at 1:30 p.m. Ms. Hayman will provide copies of the Medicaid limits on adults. Mr. Deere will assemble talking points for the discussion.

Representative Rainey said the TF will need to make a convincing argument to the legislature as to why sickle cell disease should be granted a Medicaid waiver. He noted a case argument could be made that the chronic nature of sickle cell disease requires special consideration and the lack of treatment is potentially life-threatening. It was noted that cystic fibrous receives more funding than sickle cell disease.

Mr. Deere suggested that an ad hoc group continue working on sickle cell related issues after the TF expires.

Discussion of Budgetary matters Handouts (#1 & #2)

After a lengthy discussion, Ms. Trotter made a motion to distribute the remaining \$102,000 funds in the following areas:

- **media campaign** - \$50,000 to continue educating the public about sickle cell disease through partnerships with AMHC
- **health economists** - \$27,000 for health economist, if needed
- **education** - \$25,000 for sickle cell education component to be determined by the TF

The motion was seconded by Ms. Patterson and approved by the Task Force.

Representative Rainey stressed the importance of having an evaluation component in place to evaluate the education piece. Ms. Trotter said that if the TF chose not to hire a health economist then those funds would be transferred to the media campaign component.

The TF discussed potential spokespersons for the campaign, including Scottie Thurman, Keith Jackson, and Representative Rainey.

Announcements

An event for legislators will be held in October at the Capitol Hill Building. The TF could possibly have a luncheon at this event to generate support for an Adult Sickle Cell Disease Clinical Program. This would

allow the TF focus groups to convene and discuss the TF recommendations. Representative Rainey will contact the TF when the date has been determined.

The Arkansas Minority Health Commission (AMHC) has partnered with Arkansas Sickle Cell Support Services and Partners for Inclusive Communities for a roundtable discussion September 30, 11:00 a.m.-1:00 p.m., at Philander Smith College. Ms. Trotter said that AMHC is doing a competitive art piece for sickle cell education. All individual organizations may apply to win \$25,000.

A Sickle Cell Disease Awareness campaign will be held September 18, 10:00 a.m.-2:00 p.m., at Gaines Street Baptist Church. The Pine Bluff grass root organization will convene a sickle cell forum Saturday and a banquet will be held October 7.

Next Meeting Date

The TF will meet September 8, 2010, at 1:30 p.m.

There being no further business, the meeting adjourned at 2:24 p.m.