

**MINUTES****LEGISLATIVE TASK FORCE ON SICKLE CELL DISEASE****Wednesday, August 1, 2012****10:00 a.m.****Room 272, State Capitol****Little Rock, Arkansas**

The Legislative Task Force on Sickle Cell Disease met Wednesday, August 1, 2012, in Room 272 of the State Capitol in Little Rock, Arkansas. The following members attended: Dr. David Becton, Mr. David Deere, Dr. Michelle Smith, Ms. Idonia Trotter, and Dr. Bob West.

Also attending: Senator Joyce Elliott, Robin Lockhart, and Mary Gupton.

Opening Remarks by Senator Joyce Elliott

Senator Elliott called the meeting to order. She stated that Dr. Jocelyn Elders will continue on as an ex officio member of the Task Force. She also encouraged the Task Force to be positioned and ready to make comments at the August 14<sup>th</sup> and August 15<sup>th</sup> Medicaid Subcommittee meetings that are relevant to the Task Force discussions. **Senator Elliott stated that it is crucial that the Task Force designates someone to make those comments.**

Elect Task Force Officers

The Task Force agreed to postpone electing officers until the next meeting date. Senator Elliott stated that the Task Force is waiting for the Arkansas Foundation for Medical Care (AFMC) to recommend and submit its appointee's name to fill the last position on the Task Force.

Adopt Arkansas Legislative Task Force on Sickle Cell Disease meeting Rules (Exhibit D)

After a brief discussion of the meeting rules, Senator Elliott stated that proxies are intended to be used in limited circumstances noting that the Task Force would have to approve and agree upon when to use a proxy; such as for known circumstances or crucial issues. **Ms. Trotter made the motion to amend the Task Force meeting rule (#7) to allow proxies for members with the approval of the Task Force. The motion was seconded by Dr. David Becton and the meeting rules were approved as amended.**

Review of Minutes (Exhibits E-1, E-2, E-3)

The Task Force agreed to approve the minutes with one motion. **Dr. Michelle Smith made the motion to approve the minutes. The motion was seconded by Mr. Deere and the minutes were approved.**

Discuss Task Force Goals and Objectives

Upon request by Senator Elliott, Dr. Becton gave a brief update of previous Task Force discussions regarding the adult sickle cell clinic. He stated that the Task Force had discussions regarding the adult sickle cell clinic options last year that involved physician leadership from the University of Arkansas Medical System (UAMS). Dr. Becton noted that the UAMS chancellor was reluctant to move forward with establishing the clinic without some assurance of there being enough funding to cover the costs of operating the clinic and that funding would not go away after two years. Dr. Becton stated that clinical revenue may not be sufficient to underwrite the program noting that the clinic would include a general internal medicine physician or physicians with the primary resource being hematology and palliative care as consultants. Dr. Becton noted that UAMS's general internal medicine physician was going to take the lead but has left the hospital. UAMS is interested in setting up meetings with the Task Force to further discuss this issue.

Ms. Idonia Trotter stated that the Arkansas Minority Health Commission (AMHC) commissioners unanimously voted to dedicate \$300,000 to establish the adult sickle cell clinic for fiscal year 2012. In February of 2012, AMHC gave UAMS over \$150,000 to set aside funds for the clinic. Ms. Trotter stated that AMHC is concerned about what would happen to the \$150,000 if the clinic is not implemented by the end of this biennium. She noted that AMHC requests that the funds be returned if the clinic is not established by April or May of next year. If the

clinic is established within that timeframe an additional \$75,000 has been set aside this fiscal year and next fiscal year to makeup the \$300,000. Dr. Becton stated that the funds would not be used for anything else if they were not used to establish the clinic noting that they would be returned to AMHC if the clinic is not established.

The Task Force discussed the final report recommendations and agreed to make changes according to their priorities:

**Recommendation #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.** Dr. Becton recommended changing the wording of this recommendation to read, Arkansas needs a Comprehensive Adult Sickle Cell Program. He noted the priority is to have a comprehensive program for all ages.

**Recommendation #3 - The Hubs would provide a comprehensive, multidisciplinary clinic; 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 practitioner 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. UAMS will play a big role in helping to identify and recruit individuals within the state that are willing to participate in the program. The "hub" has to be established before the "spoke". The first priority is to get the centralized location ("hub") to implement the "spoke".**

**Recommendation #4 - 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 (~0.1FTE) as well as a designated sickle cell nurse (~0.2 FTE), and would implement the patients specific plan of care, with appropriate backup from the Hub as needed. Dr. Becton stated that locating the "spokes" areas of high concentration of sickle cell patients would be based on Medicaid claims and the newborn screenings data.**

**Recommendation #5 - 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.** The Task Force briefly discussed a pilot program to promote giving waivers to sickle cell patients. The Medicaid waivers for sickle cell patients should be a high priority. Senator Elliott reiterated that the Task Force needs to designate someone to make comments about this issue before the Medicaid Subcommittee meetings on August 14<sup>th</sup> and August 15<sup>th</sup>. Dr. Becton stated that a very good case could be made that there has to be a priority of the sickle cell disease for two or three medications that does not count against the wavier, noting that standard of care and improving the quality of lives can reduce Medicaid expenditures if every adult sickle cell patient is on hydroxyurea. Senator Elliott stated that if the Task Force could show what the cost savings would be to Medicaid to care for sickle cell disease patients verses what it is now would be very powerful. Dr. West suggested that the AFMC appointee could help in this area by providing the adult sickle cell hospitalization data. Dr. Becton stated that AFMC should have access to adult sickle cell Medicaid claims for inpatient stays and emergency room visits. This medical data could show the number of adult sickle cell patients that are using hydroxyurea can reduce the number of painful crisis.

**Dr. Becton stated that the Task Force should request the Medicaid sickle cell codes and data from AFMC for the past two years. Senator Elliott asked Christean Bell, Committee Staff, to email the AFMC director**

to find out the name of the contact person that has access to this information. Senator Elliott requested that Dr. West be cc'ed on the correspondence that will be emailed. Dr. Becton and/or Dr. Saccente will also try to locate publications on the impact that hydroxyurea has had on sickle cell patients to present this information at the August 14<sup>th</sup> and August 15<sup>th</sup> committee meetings.

Senator Elliott inquired about the Department of Human Services (DHS) criteria for the sickle cell Medicaid waiver process. She recommended that Dr. Andy Allison, Director, Medical Division, DHS be contacted and invited to discuss the waiver process for the sickle cell disease at the next Task Force meeting.

**Recommendation #6 - 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.** Previously, the Task Force wanted to ensure that a coordinated effort was made to train help care learners (individuals that are in medical, nursing and other medical professional schools) to educate them about the sickle cell disease to prepare them to work in the "spokes". Mr. Deere stated that the majority of the Task Force members are doing a lot of the educational activities noting that there is not a mechanism in place to coordinate them. For educational purposes, Senator Elliott suggested that the Task Force give presentations before the following organizations to discuss and disseminate the sickle cell disease and trait information:

- Arkansas Activities Association
- Arkansas Association of Education Administrators
- Arkansas Education Association

**Recommendation #7 - Creation of a sickle cell disease registry within the Arkansas Department of Health or the University of Arkansas for Medical Sciences.** Dr. West stated that two years ago, the Task Force stressed the importance of creating a sickle cell disease registry within the Arkansas Department of Health (ADH) or at the UAMS noting that a similar registry is currently in place for cancer patients. In response to a question by Senator Elliott regarding the costs associated with creating a sickle cell registry, Dr. West replied that the Task Force would have to determine a budget. Senator Elliott asked what would be the biggest benefit of having the registry. Dr. West replied that knowing where the patients are, their health status, and whether they were keeping in contact with their healthcare providers would be helpful information to have available. Dr. Becton stressed the importance of implementing a comprehensive registry database.

Regarding the sickle cell trait information being added to the immunization records, Dr. Becton stated that the Task Force previously discussed including the sickle cell disease trait information on immunization records after an infant has been identified. Dr. West stated that this is a complex issue because the newborn screening information is generated in a different place than the registry information. The demographic information is not entered at the same time and a lot of things may not match such as misspelled names and incorrect birthdates. Dr. West noted that the idea of having the trait information included on the immunization records is not impossible noting that data experts at ADH would have to investigate this issue.

Dr. West stated that he views immunization information as a little less sensitive than individuals with the sickle cell status which is usually characterized more as genetics information whereas immunizations are not. Dr. Smith stated that the Task Force could work on this issue with the education campaign to reduce that stigma associated with the genetics. She feels that the registry should also contain sickle cell trait information.

**Recommendation #8 - Mandatory reporting of sickle disease diagnosis and health status information to the registry by physicians, laboratories, hospitals, and the state Newborn Screening Program.** Dr. West stated that the Task Force discussed previously that the newborn screening program could populate a lot of information into the registry.

**Recommendation #10 - Funding for a team of research assistants who would support principal investigators would provide a jump start for research studies. Under the supervision of senior researchers, the assistants could provide the time and expertise to collect, clean, and analyze existing data and provide the foundation for pursuing larger, grant-funded studies.** Senator Elliott suggested that the Task Force could explore the idea

of asking someone from the Clinton School of Public Health to perform some research studies to investigate what is happening to adult sickle cell patients and their quality of life.

**Recommendation #12 - Target physicians using direct mail and conferences for family practice physicians and pediatricians. The Task Force agreed to remove the words direct mail from the recommendation and keep the word conferences.** Ms. Trotter stated that the Task Force previously discussed how there were not a lot of physicians in the state that focused on the sickle cell disease. She noted the importance of educating the physicians broadly about the disease as well as the public. Senator Elliott asked if there were annual conferences in which the Task Force could present their concerns and recommendations regarding sickle cell. Ms. Trotter stated that a national annual conference is usually held around October. It was noted that The Academy of Pediatrics, American Academy of Family Physicians, and the Arkansas Medical Dental and Pharmaceutical Association have annual meetings. Senator Elliott stated that the Task Force could explore these areas as well.

**Recommendation #13 - Use schools to reach pre-teens for education about sickle cell trait and its implications for their lives.** Senator Elliott stated that the obvious way to use schools to reach pre-teens for education about sickle cell trait and its implications for their lives is through the health classes. **The Task Force needs to determine specific things that it would ask the schools to do.** Mr. Deere stated that this area was Dr. Jocelyn Elders' pet topic noting that her concerns involved individuals having children that did not know their sickle cell status. He also stated that she had suggested rescreening for many sickle cell trait cases due to many individuals not knowing their status.

**Senator Elliott suggested that the Task Force should condense all of the recommendations in the report (pages 11 and 12) into executive sentences with bold print and add the other pertinent information under it.** Mr. Deere noted that some of the recommendations were condensed and added under the key recommendations section.

#### Next Meeting Agenda Items

- **Dr. Andy Allison, Director, Medical Division, DHS**
- **Elect chairperson and vice-chair**

**Senator Elliott stated that she would ask Representative Reginald Murdoch to be a legislative ex officio member of the Task Force. She expressed that she would like to have two legislative members from the Senate and three from the House of Representatives to join the Task Force as well.**

#### New Business

Ms. Trotter noted that September is Sickle Cell Awareness month. She stated that AMHC anticipates doing an education campaign on September 1<sup>st</sup> for sickle cell disease awareness and would like to partner with the Task Force again on this project. **Senator Elliott stated that the Task Force will move forward with this.**

There being no further business, the meeting adjourned at 12:13p.m.