

By: Representatives Watson, Scott, Clark,
Gardner, Coleman (29th), Wooten

To: Public Health and Human
Services

COMMITTEE SUBSTITUTE
FOR
HOUSE BILL NO. 1250

1 AN ACT TO CREATE THE CONCERN FOR CHILDREN WITH SICKLE CELL
2 DISEASE TASK FORCE; TO PROVIDE FOR THE MEMBERSHIP OF THE TASK
3 FORCE; TO SET FORTH THE DUTIES OF THE TASK FORCE; AND FOR RELATED
4 PURPOSES.

5 WHEREAS, Sickle Cell Disease is a genetic disorder of the
6 blood that affects more than seventy-two thousand (72,000)
7 individuals in the United States; and

8 WHEREAS, it is characterized by anemia, frequent infections,
9 and unpredictable and severe pains in the back, chest, abdomen and
10 limbs; and

11 WHEREAS, the symptoms of Sickle Cell Disease may appear as
12 early as six (6) months of age and include infections, pain and
13 swelling of hands and feet, and enlargement of the abdomen and
14 heart; and

15 WHEREAS, this disease is caused by a defective gene that
16 produces an abnormal amount of hemoglobin which is the component
17 of the red blood cell responsible for oxygen transport from the
18 lungs to the tissues; and

19 WHEREAS, the disease is inherited as an autosomal recessive
20 trait and both parents must be carriers; and

21 WHEREAS, no cure for Sickle Cell Disease exists; and

22 WHEREAS, various treatments are currently available geared
23 toward minimizing the pain; and

24 WHEREAS, the Mississippi Legislature recognizes that
25 strategies for how to best identify, treat and accommodate the
26 needs of those individuals with Sickle Cell Disease and that of
27 their families are urgently needed in our state; NOW, THEREFORE,

28 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MISSISSIPPI:



29 **SECTION 1.** (1) The Concern for Children with Sickle Cell
30 Disease Task Force is created to study and make recommendations to
31 the Mississippi Legislature regarding the growing incidence of
32 Sickle Cell Disease, how to identify, treat and accommodate the
33 needs of individuals with Sickle Cell Disease and their families
34 that provide treatment, and ways to improve the delivery and
35 coordination of state services provided to individuals with Sickle
36 Cell Disease. Members of the task force shall be composed of the
37 following:

38 (a) Three (3) persons who are the parents of children
39 with Sickle Cell Disease, with one (1) such person to be appointed
40 by the Governor, one (1) to be appointed by the Lieutenant
41 Governor, and one (1) to be appointed by the Speaker of the House;

42 (b) One (1) person who is a member of the governing
43 body of a school district, to be appointed by the State
44 Superintendent of Public Education;

45 (c) One (1) person who represents the State Department
46 of Education, to be appointed by the State Superintendent of
47 Public Education;

48 (d) One (1) person who is a representative of the State
49 Department of Health, to be appointed by the executive director of
50 the department;

51 (e) One (1) person who is a representative of the
52 Sickle Cell Anemia Association, to be appointed by the executive
53 director of the association;

54 (f) One (1) person who is a representative of the
55 Mississippi Medical & Surgical Association, to be appointed by the
56 executive director of the association;

57 (g) One (1) person who is a representative of the
58 Mississippi State Medical Association, to be appointed by the
59 executive director of the association;

60 (h) One (1) person who is a representative of the
61 University of Mississippi Medical Center and who provides medical



62 or other services to individuals with Sickle Cell Disease, to be
63 appointed by the Vice Chancellor of the University of Mississippi
64 Medical Center;

65 (i) One (1) person who is a Mississippi pediatrician
66 engaged in the private practice of medicine and who provides
67 treatment to individuals with Sickle Cell Disease, to be appointed
68 by the Vice Chancellor of the University of Mississippi Medical
69 Center; and

70 (j) One (1) person who is a licensed nurse engaged in
71 the practice of nursing, to be appointed by the Executive Director
72 of the Mississippi Nurses Association.

73 (2) The task force shall:

74 (a) Review the best practices of other states with
75 regard to educational, medical and support services provided to
76 individuals diagnosed with Sickle Cell Disease and identify the
77 best practices of other states;

78 (b) Review the standard of services provided by local
79 Mississippi school districts and support programs to individuals
80 diagnosed with Sickle Cell Disease and their families, identify
81 any additional potential funding sources for school districts, and
82 identify guidelines for measurable educational and instructional
83 goals that can be used by members of the education community for
84 serving children with Sickle Cell Disease;

85 (c) Assess the medical availability of services
86 currently provided for early screening, diagnosis and treatment of
87 Sickle Cell Disease and provide recommendations for enhancing
88 medical services;

89 (d) Identify the role of higher education in developing
90 a work force in Mississippi possessing the skills necessary to
91 assist individuals with Sickle Cell Disease in medical,
92 educational, and vocational efforts or in providing additional
93 services associated with Sickle Cell Disease;



94 (e) Evaluate and identify any and all additional
95 relevant information and make legislative recommendations
96 regarding the development and implementation of a continuum of
97 educational and medical services for individuals with Sickle Cell
98 Disease; and

99 (f) File a report with those standing committees of the
100 Mississippi State Legislature and with those state agencies having
101 jurisdiction over specific recommendations of the task force, not
102 later than December 1, 2008.

103 (3) The task force shall hold its first meeting not later
104 than April 1, 2008, with the date, time and location of the
105 meeting to be designated by the Governor. At that first meeting,
106 the task force shall elect from among its membership a chairman,
107 vice chairman and any other officers determined to be necessary,
108 and shall set the date, time and location of its next meeting.

109 (4) The State Department of Health shall provide the staff
110 and other support necessary for the Concern for Children with
111 Sickle Cell Disease Task Force to perform its duties.

112 **SECTION 2.** This act shall take effect and be in force from
113 and after its passage.

