

As Introduced

**128th General Assembly
Regular Session
2009-2010**

H. B. No. 163

Representative Miller

Cosponsors: Representatives Williams, S., Boyd, Book, Chandler

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A B I L L

To amend sections 3701.131 and 3701.501 of the 1
Revised Code to establish five Ohio Sickle Cell 2
Anemia Comprehensive Treatment Centers. 3

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF OHIO:

Section 1. That sections 3701.131 and 3701.501 of the Revised 4
Code be amended to read as follows: 5

Sec. 3701.131. (A) The director of health shall do all of the 6
following: 7

~~(A)~~(1) Encourage and assist in the development of programs of 8
education and research pertaining to the causes, detection, and 9
treatment of sickle cell disease and provide for rehabilitation 10
and counseling of persons possessing the trait of or afflicted 11
with this disease; 12

~~(B)~~(2) Advise, consult, cooperate with, and assist, by 13
contract or otherwise, agencies of this state and the federal 14
government, agencies of the governments of other states, agencies 15
of political subdivisions of this state, and private 16
organizations, corporations, and associations in the development 17
and promotion of programs pertaining to the causes, detection, and 18
treatment of sickle cell disease and rehabilitation and counseling 19

of persons possessing the trait of or afflicted with this disease; 20

~~(C)~~(3) Accept and administer grants from the federal 21
government or other sources, public or private, for carrying out 22
any of the functions enumerated in divisions (A)(1) and ~~(B)~~(2) of 23
this section; 24

~~(D)~~(4) Submit a written report to the general assembly on or 25
before the twenty-first day of August of each year outlining the 26
receipt and disbursement of funds and the implementation and 27
progress of various programs undertaken pursuant to division (A) 28
of this section during the preceding fiscal year. 29

(B)(1) The director shall establish in this state five sickle 30
cell anemia comprehensive treatment centers primarily for adult 31
patients. Each center established under this division shall be 32
designated an Ohio sickle cell comprehensive treatment center and 33
shall be located at a hospital that is a primary teaching and 34
research institution associated with a medical school. 35

(2) To have a sickle cell anemia comprehensive treatment 36
center established under division (B) of this section a hospital 37
must meet all of the following requirements: 38

(a) Demonstrate commitment to the care, management, and 39
research of the disorder of sickle cell anemia and related 40
conditions; 41

(b) Have uniform management plans for the hospital's 42
emergency department care and inpatient care; 43

(c) Have established, prior to establishment of the 44
comprehensive treatment center, an outpatient sickle cell anemia 45
day hospital for alternative care of patients with sickle cell 46
anemia; 47

(d) Have a collaborative agreement with at least one of the 48
following: 49

(i) A community-based sickle-cell-anemia entity with 50
experience working with individuals, especially adults, with 51
sickle cell anemia; 52

(ii) A nonprofit entity with experience working with 53
individuals, especially adults, with sickle cell anemia. 54

(3) If funds are appropriated for this purpose, the director 55
shall annually distribute to each center established under 56
division (B) of this section funds for a full-time dedicated nurse 57
practitioner and social worker and partial salary support for a 58
medical director who is authorized by the state medical board to 59
practice medicine and surgery and osteopathic medicine and 60
surgery. 61

Sec. 3701.501. (A)(1) Except as provided in division (A)(2) 62
of this section, all newborn children shall be screened for the 63
presence of the genetic, endocrine, and metabolic disorders 64
specified in rules, adopted pursuant to this section. 65

(2) Division (A)(1) of this section does not apply if the 66
parents of the child object thereto on the grounds that the 67
screening conflicts with their religious tenets and practices. 68

(B) There is hereby created the newborn screening advisory 69
council to advise the director of health regarding the screening 70
of newborn children for genetic, endocrine, and metabolic 71
disorders. The council shall engage in an ongoing review of the 72
newborn screening requirements established under this section and 73
shall provide recommendations and reports to the director as the 74
director requests and as the council considers necessary. The 75
director may assign other duties to the council, as the director 76
considers appropriate. 77

The council shall consist of fourteen members appointed by 78
the director. In making appointments, the director shall select 79

individuals and representatives of entities with interest and 80
expertise in newborn screening, including such individuals and 81
entities as health care professionals, hospitals, children's 82
hospitals, regional genetic centers, regional sickle cell centers, 83
newborn screening coordinators, and members of the public. 84

The department of health shall provide meeting space, staff 85
services, and other technical assistance required by the council 86
in carrying out its duties. Members of the council shall serve 87
without compensation, but shall be reimbursed for their actual and 88
necessary expenses incurred in attending meetings of the council 89
or performing assignments for the council. 90

The council is not subject to sections 101.82 to 101.87 of 91
the Revised Code. 92

(C)(1) The director of health shall adopt rules in accordance 93
with Chapter 119. of the Revised Code specifying the disorders for 94
which each newborn child must be screened. 95

(2) The newborn screening advisory council shall evaluate 96
genetic, metabolic, and endocrine disorders to assist the director 97
in determining which disorders should be included in the 98
screenings required under this section. In determining whether a 99
disorder should be included, the council shall consider all of the 100
following: 101

(a) The disorder's incidence, mortality, and morbidity; 102

(b) Whether the disorder causes disability if diagnosis, 103
treatment, and early intervention are delayed; 104

(c) The potential for successful treatment of the disorder; 105

(d) The expected benefits to children and society in relation 106
to the risks and costs associated with screening for the disorder; 107

(e) Whether a screening for the disorder can be conducted 108
without taking an additional blood sample or specimen. 109

(3) Based on the considerations specified in division (C)(2) 110
of this section, the council shall make recommendations to the 111
director of health for the adoption of rules under division (C)(1) 112
of this section. The director shall promptly and thoroughly review 113
each recommendation the council submits. 114

(D) The director shall adopt rules in accordance with Chapter 115
119. of the Revised Code establishing standards and procedures for 116
the screenings required by this section. The rules shall include 117
standards and procedures for all of the following: 118

(1) Causing rescreenings to be performed when initial 119
screenings have abnormal results; 120

(2) Designating the person or persons who will be responsible 121
for causing screenings and rescreenings to be performed; 122

(3) Giving to the parents of a child notice of the required 123
initial screening and the possibility that rescreenings may be 124
necessary; 125

(4) Communicating to the parents of a child the results of 126
the child's screening and any rescreenings that are performed; 127

(5) Giving notice of the results of an initial screening and 128
any rescreenings to the person who caused the child to be screened 129
or rescreened, or to another person or government entity when the 130
person who caused the child to be screened or rescreened cannot be 131
contacted; 132

(6) Referring children who receive abnormal screening or 133
rescreening results to providers of follow-up services, including 134
the services made available through funds disbursed under division 135
(F) of this section. 136

(E)(1) Except as provided in divisions (E)(2) and (3) of this 137
section, all newborn screenings required by this section shall be 138
performed by the public health laboratory authorized under section 139

3701.22 of the Revised Code. 140

(2) If the director determines that the public health 141
laboratory is unable to perform screenings for all of the 142
disorders specified in the rules adopted under division (C) of 143
this section, the director shall select another laboratory to 144
perform the screenings. The director shall select the laboratory 145
by issuing a request for proposals. The director may accept 146
proposals submitted by laboratories located outside this state. At 147
the conclusion of the selection process, the director shall enter 148
into a written contract with the selected laboratory. If the 149
director determines that the laboratory is not complying with the 150
terms of the contract, the director shall immediately terminate 151
the contract and another laboratory shall be selected and 152
contracted with in the same manner. 153

(3) Any rescreening caused to be performed pursuant to this 154
section may be performed by the public health laboratory or one or 155
more other laboratories designated by the director. Any laboratory 156
the director considers qualified to perform rescreenings may be 157
designated, including a laboratory located outside this state. If 158
more than one laboratory is designated, the person responsible for 159
causing a rescreening to be performed is also responsible for 160
selecting the laboratory to be used. 161

(F)(1) The director shall adopt rules in accordance with 162
Chapter 119. of the Revised Code establishing a fee that shall be 163
charged and collected in addition to or in conjunction with any 164
laboratory fee that is charged and collected for performing the 165
screenings required by this section. The fee, which shall be not 166
less than fourteen dollars, shall be disbursed as follows: 167

(a) Not less than ten dollars and twenty-five cents shall be 168
deposited in the state treasury to the credit of the genetics 169
services fund, which is hereby created. Not less than seven 170
dollars and twenty-five cents of each fee credited to the genetics 171

services fund shall be used to defray the costs of the programs 172
authorized by section 3701.502 of the Revised Code. Not less than 173
three dollars from each fee credited to the genetics services fund 174
shall be used to defray costs of phenylketonuria programs. 175

(b) Not less than three dollars and seventy-five cents shall 176
be deposited into the state treasury to the credit of the sickle 177
cell fund, which is hereby created. Money credited to the sickle 178
cell fund shall be used to defray costs of programs authorized by 179
division (A) of section 3701.131 of the Revised Code. 180

(2) In adopting rules under division (F)(1) of this section, 181
the director shall not establish a fee that differs according to 182
whether a screening is performed by the public health laboratory 183
or by another laboratory selected by the director pursuant to 184
division (E)(2) of this section. 185

Section 2. That existing sections 3701.131 and 3701.501 of 186
the Revised Code are hereby repealed. 187

Section 3. The General Assembly finds that establishment of 188
Ohio Sickle Cell Comprehensive Treatment Centers, as required by 189
this act's amendment of section 3701.131 of the Revised Code, is 190
likely to reduce the cost of treating a patient with sickle cell 191
anemia and that this cost was, on average in 2004, \$6,223 per 192
hospitalization of a patient with sickle cell anemia. 193