

As Introduced

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H. B. No. 183

Representative Barnes

Cosponsor: Representative Patmon

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A B I L L

To amend sections 3701.501 and 3701.503 of the 1
Revised Code to codify the genetic, endocrine, and 2
metabolic disorders screened for under the 3
existing Newborn Screening Program and to declare 4
an emergency. 5

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

Section 1. That sections 3701.501 and 3701.503 of the Revised 6
Code be amended to read as follows: 7

Sec. 3701.501. (A)(1) Except as provided in division (A)(2) 8
of this section, all newborn children shall be screened for the 9
presence of the genetic, endocrine, and metabolic disorders 10
specified in ~~rules, adopted pursuant to~~ division (C) of this 11
section. 12

(2) Division (A)(1) of this section does not apply if the 13
parents of the child object thereto on the grounds that the 14
screening conflicts with their religious tenets and practices. 15

(B) There is hereby created the newborn screening advisory 16
council to advise the director of health regarding the screening 17
of newborn children for genetic, endocrine, and metabolic 18
disorders. The council shall engage in an ongoing review of the 19

newborn screening requirements established under this section and 20
shall provide recommendations and reports to the director as the 21
director requests and as the council considers necessary. The 22
director may assign other duties to the council, as the director 23
considers appropriate. 24

The council shall consist of fourteen members appointed by 25
the director. In making appointments, the director shall select 26
individuals and representatives of entities with interest and 27
expertise in newborn screening, including such individuals and 28
entities as health care professionals, hospitals, children's 29
hospitals, regional genetic centers, regional sickle cell centers, 30
newborn screening coordinators, and members of the public. 31

The department of health shall provide meeting space, staff 32
services, and other technical assistance required by the council 33
in carrying out its duties. Members of the council shall serve 34
without compensation, but shall be reimbursed for their actual and 35
necessary expenses incurred in attending meetings of the council 36
or performing assignments for the council. 37

The council is not subject to sections 101.82 to 101.87 of 38
the Revised Code. 39

~~(C)(1) The director of health shall adopt rules in accordance 40
with Chapter 119. of the Revised Code specifying the disorders for 41
which each newborn child must be screened. 42~~

~~(2) The newborn screening advisory council shall evaluate 43
genetic, metabolic, and endocrine disorders to assist the director 44
in determining which disorders should be included in the 45
screenings required under this section. In determining whether a 46
disorder should be included, the council shall consider all of the 47
following: 48~~

~~(a) The disorder's incidence, mortality, and morbidity; 49~~

~~(b) Whether the disorder causes disability if diagnosis, 50~~

treatment, and early intervention are delayed;	51
(c) The potential for successful treatment of the disorder;	52
(d) The expected benefits to children and society in relation to the risks and costs associated with screening for the disorder;	53 54
(e) Whether a screening for the disorder can be conducted without taking an additional blood sample or specimen.	55 56
(3) Based on the considerations specified in division (C)(2) of this section, the council shall make recommendations to the director of health for the adoption of rules under division (C)(1) of this section. The director shall promptly and thoroughly review each recommendation the council submits <u>Each hospital and freestanding birthing center shall screen a newborn born in the hospital or center for the presence of all of the following genetic, endocrine, or metabolic disorders:</u>	57 58 59 60 61 62 63 64
(1) <u>Argininemia;</u>	65
(2) <u>Argininosuccinic acidemia;</u>	66
(3) <u>Biotinidase deficiency;</u>	67
(4) <u>Carnitine/acylcarnitine translocase deficiency;</u>	68
(5) <u>Carnitine palmitoyl transferase deficiency type II;</u>	69
(6) <u>Carnitine uptake defect;</u>	70
(7) <u>Citrullinemia;</u>	71
(8) <u>Congenital adrenal hyperplasia;</u>	72
(9) <u>Congenital hypothyroidism;</u>	73
(10) <u>Cystic fibrosis;</u>	74
(11) <u>Galactosemia;</u>	75
(12) <u>Glutaric acidemia type I;</u>	76
(13) <u>Glutaric acidemia type II;</u>	77

<u>(14) Homocystinuria (cystathionine-beta-synthase deficiency);</u>	78
<u>(15) Hypermethioninemia;</u>	79
<u>(16) Isobutyryl-CoA dehydrogenase deficiency;</u>	80
<u>(17) Isovaleric acidemia;</u>	81
<u>(18) Long chain hydroxyacyl-CoA dehydrogenase deficiency;</u>	82
<u>(19) Maple syrup urine disease;</u>	83
<u>(20) Medium chainacyl-CoA dehydrogenase deficiency;</u>	84
<u>(21) Methylmalonic acidemia;</u>	85
<u>(22) Multiple CoA carboxylase deficiency;</u>	86
<u>(23) Phenylketonuria;</u>	87
<u>(24) Propionic acidemia;</u>	88
<u>(25) Short chain acyl-CoA dehydrogenase deficiency;</u>	89
<u>(26) Trifunctional protein deficiency;</u>	90
<u>(27) Tyrosinemia type-I;</u>	91
<u>(28) Tyrosinemia type-II;</u>	92
<u>(29) Tyrosinemia type-III;</u>	93
<u>(30) Very long chain acyl-CoA dehydrogenase deficiency;</u>	94
<u>(31) 2-methylbutyryl-CoA dehydrogenase deficiency;</u>	95
<u>(32) 3-hydroxy-3-methylglutaryl-CoA lyase deficiency;</u>	96
<u>(33) 3-ketothiolase deficiency;</u>	97
<u>(34) 3-methylcrotonyl-CoA carboxylase deficiency;</u>	98
<u>(35) Sickle cell and other hemoglobinopathies.</u>	99
(D) The director shall adopt rules in accordance with Chapter	100
119. of the Revised Code establishing standards and procedures for	101
the screenings required by this section. The rules shall include	102
standards and procedures for all of the following:	103

(1) Causing rescreenings to be performed when initial screenings have abnormal results;	104 105
(2) Designating the person or persons who will be responsible for causing screenings and rescreenings to be performed;	106 107
(3) Giving to the parents of a child notice of the required initial screening and the possibility that rescreenings may be necessary;	108 109 110
(4) Communicating to the parents of a child the results of the child's screening and any rescreenings that are performed <u>and giving to the child's parents information on each disorder for which the child's screening or rescreening result was abnormal;</u>	111 112 113 114
(5) Giving notice of the results of an initial screening and any rescreenings to the person who caused the child to be screened or rescreened, or to another person or government entity when the person who caused the child to be screened or rescreened cannot be contacted;	115 116 117 118 119
(6) Referring children who receive abnormal screening or rescreening results to providers of follow-up services, including the services made available through funds disbursed under division (F) of this section.	120 121 122 123
(E)(1) Except as provided in divisions (E)(2) and (3) of this section, all newborn screenings required by this section shall be performed by the public health laboratory authorized under section 3701.22 of the Revised Code.	124 125 126 127
(2) If the director determines that the public health laboratory is unable to perform screenings for all of the disorders specified in the rules adopted under division (C) of this section, the director shall select another laboratory to perform the screenings. The director shall select the laboratory by issuing a request for proposals. The director may accept proposals submitted by laboratories located outside this state. At	128 129 130 131 132 133 134

the conclusion of the selection process, the director shall enter 135
into a written contract with the selected laboratory. If the 136
director determines that the laboratory is not complying with the 137
terms of the contract, the director shall immediately terminate 138
the contract and another laboratory shall be selected and 139
contracted with in the same manner. 140

(3) Any rescreening caused to be performed pursuant to this 141
section may be performed by the public health laboratory or one or 142
more other laboratories designated by the director. Any laboratory 143
the director considers qualified to perform rescreenings may be 144
designated, including a laboratory located outside this state. If 145
more than one laboratory is designated, the person responsible for 146
causing a rescreening to be performed is also responsible for 147
selecting the laboratory to be used. 148

(F)(1) The director shall adopt rules in accordance with 149
Chapter 119. of the Revised Code establishing a fee that shall be 150
charged and collected in addition to or in conjunction with any 151
laboratory fee that is charged and collected for performing the 152
screenings required by this section. The fee, which shall be not 153
less than fourteen dollars, shall be disbursed as follows: 154

(a) Not less than ten dollars and twenty-five cents shall be 155
deposited in the state treasury to the credit of the genetics 156
services fund, which is hereby created. Not less than seven 157
dollars and twenty-five cents of each fee credited to the genetics 158
services fund shall be used to defray the costs of the programs 159
authorized by section 3701.502 of the Revised Code. Not less than 160
three dollars from each fee credited to the genetics services fund 161
shall be used to defray costs of phenylketonuria programs. 162

(b) Not less than three dollars and seventy-five cents shall 163
be deposited into the state treasury to the credit of the sickle 164
cell fund, which is hereby created. Money credited to the sickle 165
cell fund shall be used to defray costs of programs authorized by 166

section 3701.131 of the Revised Code. 167

(2) In adopting rules under division (F)(1) of this section, 168
the director shall not establish a fee that differs according to 169
whether a screening is performed by the public health laboratory 170
or by another laboratory selected by the director pursuant to 171
division (E)(2) of this section. 172

Sec. 3701.503. As used in section 3701.501 and sections 173
3701.504 to 3701.509 of the Revised Code: 174

(A) "Parent" means either parent, unless the parents are 175
separated or divorced or their marriage has been dissolved or 176
annulled, in which case "parent" means the parent who is the 177
residential parent and legal custodian. 178

(B) "Guardian" has the same meaning as in section 2111.01 of 179
the Revised Code. 180

(C) "Custodian" means, except as used in division (A) of this 181
section, a government agency or an individual, other than the 182
parent or guardian, with legal or permanent custody of a child as 183
defined in section 2151.011 of the Revised Code. 184

(D) "Hearing screening" means the identification of newborns 185
and infants who may have a hearing impairment, through the use of 186
a physiologic test. 187

(E) "Hearing evaluation" means evaluation through the use of 188
audiological procedures by an audiologist or physician. 189

(F) "Hearing impairment" means a loss of hearing in one or 190
both ears in the frequency region important for speech recognition 191
and comprehension. 192

(G) "Newborn" means a child who is less than thirty days old. 193

(H) "Infant" means a child who is at least thirty days but 194
less than twenty-four months old. 195

(I) "Freestanding birthing center" has the same meaning as in section 3702.141 of the Revised Code.	196 197
(J) "Physician" means an individual authorized under Chapter 4731. of the Revised Code to practice medicine and surgery or osteopathic medicine and surgery.	198 199 200
(K) "Audiologist" means an individual authorized under section 4753.07 of the Revised Code to practice audiology.	201 202
(L) "Hospital" means a hospital that has a maternity unit or newborn nursery.	203 204
(M) "Maternity unit" means any unit or place in a hospital where women are regularly received and provided care during all or part of the maternity cycle, except that "maternity unit" does not include an emergency department or similar place dedicated to providing emergency health care.	205 206 207 208 209
(N) "Board of health" means the board of health of a city or general health district or the authority having the duties of a board of health under section 3709.05 of the Revised Code.	210 211 212
Section 2. That existing sections 3701.501 and 3701.503 of the Revised Code are hereby repealed.	213 214
Section 3. This act is hereby declared to be an emergency measure necessary for the immediate preservation of the public peace, health, and safety. The reason for such necessity is that many of the disorders included in the Newborn Screening Program panel cannot be detected by merely observing a newborn and early detection of a disorder soon after birth can help prevent serious problems, including brain damage, organ damage, and even death.	215 216 217 218 219 220 221