

- 1 HB77
- 2 4VUHR33-2
- 3 By Representative Rigsby
- 4 RFD: Health
- 5 First Read: 06-Feb-24
- 6 PFD: 01-Feb-24



1 <u>Enrolled</u>, An Act,

| 2 | Relating to newborn screening; to amend Section |
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| 3 | 22-20-3, Code of Alabama 1975; to add Section 22-20-3.2 to the |
| 4 | Code of Alabama 1975; to provide Legislative Findings; to |
| 5 | require newborns with a family history of a disease to be |
| 6 | tested for that disease under certain circumstances; to |
| 7 | require conditions on the Recommended Uniform Screening Panel |
| 8 | (RUSP) to be included on the Newborn Screening Panel; to |
| 9 | provide a timeline for the addition of RUSP-approved condition |
| 10 | on the panel; to require the State Board of Health to adopt |
| 11 | rules relating to the newborn screening program; and to |
| 12 | condition testing for heritable diseases and conditions by the |
| 13 | State Laboratory on the availability of funding. |
| 14 | BE IT ENACTED BY THE LEGISLATURE OF ALABAMA: |
| 15 | Section 1. (a) This act shall be known and may be cited |
| 16 | as the Zachary Thomas Newborn Screening Act. |
| 17 | (b) The Legislature finds and declares that: |
| 18 | (1) Babies born in Alabama are currently screened for |
| 19 | some, but not all, conditions included on the United States |
| 20 | Department of Human Services' Recommended Uniform Screening |
| 21 | Panel (RUSP). |
| 22 | (2) New conditions are added to the RUSP on a regular |
| 23 | basis, and the Department of Public Health is firmly committed |
| 24 | to adding RUSP conditions to the state's newborn screening |
| 25 | panel. |
| 26 | (3) It is in the best interest of the state to continue |

(3) It is in the best interest of the state to continue
to support the State Laboratory and its important mission of
newborn screening.



| 29 | Section 2. Section 22-20-3, Code of Alabama 1975, is |
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| 30 | amended to read as follows: |
| 31 | "§22-20-3 |
| 32 | (a) For the purposes of this section, the following |
| 33 | terms have the following meanings: |
| 34 | (1) BOARD. The Alabama State Board of Health. |
| 35 | (2) NEWBORN SCREENING PANEL or PANEL. The list of |
| 36 | conditions that the State of Alabama screens for as part of |
| 37 | the Newborn Screening Program. |
| 38 | (3) NEWBORN SCREENING PROGRAM or PROGRAM. The |
| 39 | Department of Public Health's program that tests newborn |
| 40 | children for conditions on the Newborn Screening Panel and |
| 41 | identifies newborn children that may have those conditions. |
| 42 | (4) RUSP. The Recommended Uniform Screening Panel |
| 43 | recommended by the Secretary of the Department and Health and |
| 44 | Human Services for states to screen as part of their newborn |
| 45 | screening programs. |
| 46 | (5) STATE LABORATORY. The Bureau of Clinical |
| 47 | Laboratories within the Department of Public Health. |
| 48 | (b) It shall be the duty of the The administrative |
| 49 | officer <u>,</u> or other <u>persons</u> individuals in charge of each |
| 50 | institution caring for _infants _newborn_children_28_days _or |
| 51 | less of age old or younger , or the physician attending a |
| 52 | newborn child <u>,</u> or the <u>person</u> individual attending a newborn |
| 53 | child that was not attended by a physician to shall cause to |
| 54 | have administered to every such infant or newborn child in his |
| 55 | or her care: (i) testing for any disease for which the newborn |
| 56 | has a known family history and which can be diagnosed at |

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57 birth; and (ii) a reliable test for conditions on the Newborn 58 Screening Panel, including hypothyroidism and a reliable test for phenylketonuria (PKU), such as the Guthrie test, or any 59 60 other test considered equally reliable by the State Board of Health and a reliable test for sickle cell anemia, sickle cell 61 62 trait, and/or abnormal hemoglobin and such other tests 63 relating to mental retardation or other genetic, metabolic, or 64 other heritable diseases and conditions as are designated 65 approved for inclusion on the Newborn Screening Panel by the Board of Health board, pursuant to Section 22-20-3.2,-66 67 Provided provided, however, that the Board of Health board shall designate only conditions that are detectable by mass 68 screening of newborn infants children. Initial mass screening 69 tests and the recording of results shall be performed by the 70 71 Public Health State Laboratory at such times and in such manner as may be prescribed by the State Board of Health; 72 73 board and confirmatory tests shall be undertaken by such 74 laboratory facilities as are designated by the attending 75 physician or parent; provided, that no such initial.

76 (c) No screening or confirmatory tests shall be given 77 to any newborn child whose parent or parents object thereto on 78 the grounds that such the screening or tests conflict with 79 their religious tenets and practices. In the event a test is 80 not given to a newborn child on account of such objections by 81 the his or her parent or parents, then no physician, nurse, laboratory technician, person individual administering tests, 82 hospital, institution, or other health care provider shall be 83 84 liable for failure to administer the test.

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| 85 | (b) (d) The State Board of Health board shall promulgate |
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| 86 | such adopt rules and regulations as it considers necessary to |
| 87 | provide for the care and treatment of those newborn infants |
| 88 | <u>children</u> whose tests are determined positive, including, but |
| 89 | not limited to, advising dietary treatment for such infants |
| 90 | <u>newborn children</u> . The State Board of Health board shall |
| 91 | promulgate adopt any other rules and regulations necessary to |
| 92 | effectuate the provisions of this section, including the |
| 93 | collection of a reasonable fee for the newborn child screening |
| 94 | program." |
| 95 | Section 3. Section 22-20-3.2 is added to the Code of |
| 96 | Alabama 1975, to read as follows: |
| 97 | \$22-20-3.2 |
| 98 | (a) This section shall have the same definitions as |
| 99 | Section 22-20-3, Code of Alabama 1975. |
| 100 | (b) The board shall adopt rules to administer the use |
| 101 | of the Newborn Screening Panel, including the conditions for |
| 102 | which screening is required. The Newborn Screening Panel shall |
| 103 | include, but not be limited to, those conditions listed on the |
| 104 | RUSP. Nothing in this act precludes the board from adding |
| 105 | conditions to the Newborn Screening Panel that do not appear |
| 106 | on the RUSP. |
| 107 | (c)(1) No later than 36 months following the approval |
| 108 | and addition of a new condition to the RUSP, the board shall |
| 109 | add the condition to the Newborn Screening Panel and implement |
| 110 | and administer screening. |
| 111 | (2) Any condition added to the RUSP prior to January 1, |
| 112 | 2024, shall be added to the panel by the board no later than |
| | |



113 October 1, 2027.

(3) In the event that a RUSP-approved condition is not added to the Newborn Screening Panel in the time frame required by this subsection, the board shall provide a written notice to the State Health Officer outlining the reasons for the delay. Following its presentation to the State Health Officer, the board shall post the same written notice on its website.

(d) Testing for heritable diseases and conditions and the services and facilities required for testing shall be subject to the availability of funding and workforce in the State Laboratory, as determined by the board.

Section 4. This act shall become effective on October 126 1, 2024.



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| 134 | | Speaker of the House of Repre | esentatives | | | |
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| 139 | | President and Presiding Officer | of the Senate | | | |
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| 144 | | hereby certify that the within A | Act originated in and | | | |
| 145 | was passed by the House 22-Feb-24. | | | | | |
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| 147 | John Treadwell | | | | | |
| 148 | | Clerk | | | | |
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| 154 | Senate | 25-Apr-24 | Amended and Passed | | | |
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| 156 | House | 25-Apr-24 | Concurred in Senate | | | |
| 157 | | | Amendment | | | |
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