

- 1 SB256
- 2 5PJJ636-1
- 3 By Senators Smitherman, Singleton
- 4 RFD: Children and Youth Health
- 5 First Read: 21-Mar-24



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4	SYNOPSIS:
5	Under existing law, each newborn child is
6	screened for certain heritable diseases and conditions,
7	as determined by the Alabama State Board of Health.
8	This bill would require the State Board of
9	Health to add any condition on the Recommended Uniform
L 0	Screening Panel (RUSP).
L1	This bill would require the State Board of
L2	Health to adopt rules relating to the use of the
13	Newborn Screening Panel.
L 4	This bill would provide a timeline for
L 5	conditions with RUSP approval to be included on the
L 6	panel and would require a written report to the State
L 7	Health Officer if the timeline is not met.
L 8	This bill would also provide that the duties of
L 9	the State Laboratory relating to testing for certain
20	heritable diseases and conditions are contingent on the
21	availability of funding.
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24	A BILL
25	TO BE ENTITLED
26	AN ACT
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Relating to newborn screening; to amend Section

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- 29 22-20-3, Code of Alabama 1975; to add Section 22-20-3.2 to the
- 30 Code of Alabama 1975; to provide Legislative Findings; to
- 31 require conditions on the Recommended Uniform Screening Panel
- 32 (RUSP) to be included on the Newborn Screening Panel; to
- provide a timeline for the addition of RUSP-approved condition
- on the panel; to require the State Board of Health to adopt
- 35 rules relating to the newborn screening program; and to
- 36 condition testing for heritable diseases and conditions by the
- 37 State Laboratory on the availability of funding.
- 38 BE IT ENACTED BY THE LEGISLATURE OF ALABAMA:
- 39 Section 1. (a) This act shall be known and may be cited
- 40 as the Zachary Thomas Newborn Screening Act.
- 41 (b) The Legislature finds and declares that:
- 42 (1) Babies born in Alabama are currently screened for
- 43 some, but not all, conditions included on the United States
- 44 Department of Human Services' Recommended Uniform Screening
- 45 Panel (RUSP).
- 46 (2) New conditions are added to the RUSP on a regular
- 47 basis, and the Department of Public Health is firmly committed
- 48 to adding RUSP conditions to the state's newborn screening
- 49 panel.
- 50 (3) It is in the best interest of the state to continue
- 51 to support the State Laboratory and its important mission of
- 52 newborn screening.
- 53 Section 2. Section 22-20-3, Code of Alabama 1975, is
- 54 amended to read as follows:
- 55 **"**\$22-20-3
- 56 (a) For the purposes of this section, the following



57	terms	have	the	following	meanings:

- (1) BOARD. The Alabama State Board of Health.
- (2) NEWBORN SCREENING PANEL or PANEL. The list of
 conditions that the State of Alabama screens for as part of
 the Newborn Screening Program.
- 62 (3) NEWBORN SCREENING PROGRAM or PROGRAM. The
 63 Department of Public Health's program that tests newborn
 64 children for conditions on the Newborn Screening Panel and
 65 identifies newborn children that may have those conditions.
 - (4) RUSP. The Recommended Uniform Screening Panel recommended by the Secretary of the Department and Health and Human Services for states to screen as part of their newborn screening programs.
 - (5) STATE LABORATORY. The Bureau of Clinical Laboratories within the Department of Public Health.
 - (b) It shall be the duty of the The administrative officer, or other persons individuals in charge of each institution caring for infants newborn children 28 days or less of age old or younger, or the physician attending a newborn child, or the person individual attending a newborn child that was not attended by a physician to shall cause to have administered to every such infant or newborn child in his or her care a reliable test for conditions on the Newborn Screening Panel, including hypothyroidism and a reliable test for phenylketonuria (PKU), such as the Cuthric test, or any other test considered equally reliable by the State Board of Health and a reliable test for sickle cell anemia, sickle cell trait, and/or abnormal hemoglobin and such other tests

THE SERVICE

85	relating to mental retardation or other genetic, metabolic, or
86	other heritable diseases—and conditions as—are designated
87	approved for inclusion on the Newborn Screening Panel by the
88	Board of Health board, pursuant to Section 22-20-3.2,-
89	Provided provided, however, that the Board of Health board
90	shall designate only conditions that are detectable by mass
91	screening of newborn <u>infants</u> children. Initial mass screening
92	tests and the recording of results shall be performed by the
93	Public Health State Laboratory at such times and in such
94	manner as may be prescribed by the State Board of Health;
95	<pre>board and confirmatory tests shall be undertaken by such</pre>
96	laboratory facilities as-are designated by the attending
97	physician or parent; provided, that no such initial.
98	(c) No screening or confirmatory tests shall be given
99	to any <pre>newborn child whose parent or parents object thereto</pre> on
100	the grounds that such the screening or tests conflict with
101	their religious tenets and practices. In the event a test is
102	not given to a <pre>newborn child on account of such objections by</pre>
103	the his or her parent or parents, then no physician, nurse,
104	laboratory technician, <pre>person</pre> <pre>individual</pre> administering tests,
105	hospital, institution $\underline{}$ or other health care provider shall be
106	liable for failure to administer the test.
107	(b) (d) The State Board of Health board shall promulgate
108	<pre>such adopt rules and regulations as it considers necessary to</pre>
109	provide for the care and treatment of those newborn infants
110	$\underline{\text{children}}$ whose tests are determined positive, including, but
111	not limited to, advising dietary treatment for such infants
112	newborn children. The State Board of Health board shall



- 113 promulgate adopt any other rules and regulations necessary to
- 114 effectuate the provisions of this section, including the
- 115 collection of a reasonable fee for the newborn child screening
- 116 program."
- 117 Section 3. Section 22-20-3.2 is added to the Code of
- 118 Alabama 1975, to read as follows:
- 119 \$22-20-3.2
- 120 (a) This section shall have the same definitions as
- 121 Section 22-20-3, Code of Alabama 1975.
- 122 (b) The board shall adopt rules to administer the use
- of the Newborn Screening Panel, including the conditions for
- which screening is required. The Newborn Screening Panel shall
- include, but not be limited to, those conditions listed on the
- 126 RUSP. Nothing in this act precludes the board from adding
- 127 conditions to the Newborn Screening Panel that do not appear
- 128 on the RUSP.
- 129 (c) (1) No later than 36 months following the approval
- and addition of a new condition to the RUSP, the board shall
- add the condition to the Newborn Screening Panel and implement
- and administer screening.
- 133 (2) Any condition added to the RUSP prior to January 1,
- 134 2024, shall be added to the panel by the board no later than
- 135 October 1, 2027.
- 136 (3) In the event that a RUSP-approved condition is not
- 137 added to the Newborn Screening Panel in the time frame
- 138 required by this subsection, the board shall provide a written
- 139 notice to the State Health Officer outlining the reasons for
- 140 the delay. Following its presentation to the State Health



141	Officer,	the	board	shall	post	the	same	written	notice	on	its
142	website.										

- 143 (d) Testing for heritable diseases and conditions and
 144 the services and facilities required for testing shall be
 145 subject to the availability of funding and workforce in the
 146 State Laboratory, as determined by the board.
- Section 4. This act shall become effective on October 148 1, 2024.