

Second Regular Session
Seventy-first General Assembly
STATE OF COLORADO

PREAMENDED

This Unofficial Version Includes Committee
Amendments Not Yet Adopted on Second Reading

LLS NO. 18-0435.01 Kristen Forrestal x4217

HOUSE BILL 18-1006

HOUSE SPONSORSHIP

Hamner and Liston,

SENATE SPONSORSHIP

Gardner and Moreno,

House Committees

Public Health Care & Human Services
Finance
Appropriations

Senate Committees

A BILL FOR AN ACT

101 **CONCERNING MODIFICATIONS TO THE NEWBORN SCREENING PROGRAM**
102 **ADMINISTERED BY THE DEPARTMENT OF PUBLIC HEALTH AND**
103 **ENVIRONMENT, AND, IN CONNECTION THEREWITH, MAKING AN**
104 **APPROPRIATION.**

Bill Summary

(Note: This summary applies to this bill as introduced and does not reflect any amendments that may be subsequently adopted. If this bill passes third reading in the house of introduction, a bill summary that applies to the reengrossed version of this bill will be available at <http://leg.colorado.gov>.)

The bill updates the current newborn screening program to require more timely newborn hearing screenings. The department of public health and environment is authorized to assess a fee for newborn screening and

Shading denotes HOUSE amendment. Double underlining denotes SENATE amendment.
Capital letters or bold & italic numbers indicate new material to be added to existing statute.
Dashes through the words indicate deletions from existing statute.

necessary follow-up services. The bill creates the newborn hearing screening cash fund for the purpose of covering the costs of the program.

1 *Be it enacted by the General Assembly of the State of Colorado:*

2 **SECTION 1.** In Colorado Revised Statutes, **repeal** part 8 of
3 article 4 of title 25.

4 **SECTION 2.** In Colorado Revised Statutes, **amend** 25-4-1002 as
5 follows:

6 **25-4-1002. Legislative declaration.** (1) The general assembly
7 hereby finds and declares that:

8 (a) RECENT NEWBORN SCREENING INNOVATIONS ARE CONSIDERED
9 AMONG THE GREATEST PUBLIC HEALTH ACHIEVEMENTS OF THE
10 TWENTY-FIRST CENTURY;

11 (b) SCIENTIFIC RESEARCH HAS DEMONSTRATED THAT NEWBORN
12 SCREENING NOT ONLY SAVES LIVES AND IMPROVES DEVELOPMENTAL
13 OUTCOMES BUT ALSO CONTRIBUTES TO COST SAVINGS FOR FAMILIES,
14 HEALTH CARE SYSTEMS, AND THE STATE;

15 (c) NEWBORN SCREENING INCLUDES CONDITIONS FOR WHICH
16 DIAGNOSIS AND TREATMENT MUST BE IMPLEMENTED IN A TIMELY MANNER
17 IN ORDER TO ACHIEVE MAXIMUM BENEFIT FOR THE CHILD;

18 (d) NEWBORN SCREENING IS AN APPROPRIATE PUBLIC HEALTH
19 FUNCTION TO PROVIDE NECESSARY EDUCATIONAL SERVICES TO HEALTH
20 CARE PROVIDERS, FAMILIES, AND COMMUNITIES SO THAT APPROPRIATE
21 RESOURCES AND INFORMATION ARE AVAILABLE;

22 (e) NEWBORN SCREENING IS A PUBLIC HEALTH FUNCTION THAT
23 IDENTIFIES NEWBORNS AT RISK OF CERTAIN CONDITIONS OR HEARING LOSS,
24 AS WELL AS NEWBORNS WHO DO NOT RECEIVE SCREENING, AND
25 APPROPRIATELY CONNECTS THEM TO CARE;

1 (f) AN EFFECTIVE NEWBORN SCREENING PROGRAM IS DEPENDENT
2 UPON A STRONG SYSTEM OF EDUCATION AND COORDINATION AMONG
3 PRIMARY CARE PROVIDERS, HOSPITALS, SPECIALTY CARE PROVIDERS,
4 PATIENT AND FAMILY SUPPORT ORGANIZATIONS, PUBLIC HEALTH
5 LABORATORY STAFF, AND PUBLIC HEALTH PROFESSIONALS;

6 (a) (g) State policy regarding newborn screening and genetic
7 counseling and education should be made with full public knowledge, in
8 light of expert opinion, and should be constantly reviewed to consider
9 changing medical knowledge and ensure full public protection;

10 (b) (h) Participation of persons in genetic counseling programs in
11 this state should be wholly voluntary and that all information obtained
12 from persons involved in such programs or in newborn screening
13 programs in the state should be held strictly confidential.

14 (i) HEARING LOSS OCCURS IN NEWBORN INFANTS MORE
15 FREQUENTLY THAN ANY OTHER HEALTH CONDITION FOR WHICH NEWBORN
16 INFANT SCREENING IS REQUIRED;

17 (j) EIGHTY PERCENT OF THE LANGUAGE ABILITY OF A CHILD IS
18 ESTABLISHED BY THE TIME THE CHILD IS EIGHTEEN MONTHS OF AGE, AND
19 IT IS VITALLY IMPORTANT TO SUPPORT THE HEALTHY DEVELOPMENT OF
20 LANGUAGE SKILLS;

21 (k) EARLY DETECTION, EARLY INTERVENTION, AND TREATMENT OF
22 HEARING LOSS IN A CHILD ARE HIGHLY EFFECTIVE IN FACILITATING A
23 CHILD'S HEALTHY DEVELOPMENT IN A MANNER CONSISTENT WITH THE
24 CHILD'S AGE AND COGNITIVE ABILITY;

25 (l) CHILDREN WITH HEARING LOSS WHO DO NOT RECEIVE EARLY
26 INTERVENTION AND TREATMENT FREQUENTLY REQUIRE SPECIAL
27 EDUCATIONAL SERVICES, WHICH, FOR THE VAST MAJORITY OF CHILDREN

1 IN THE STATE WITH HEARING NEEDS, ARE PUBLICLY FUNDED; AND

2 (m) APPROPRIATE TESTING AND IDENTIFICATION OF NEWBORN
3 INFANTS WITH HEARING LOSS WILL FACILITATE EARLY INTERVENTION AND
4 TREATMENT AND WILL THEREFORE SERVE THE PUBLIC PURPOSES OF
5 PROMOTING THE HEALTHY DEVELOPMENT OF CHILDREN AND REDUCING
6 THE NEED FOR ADDITIONAL PUBLIC EXPENDITURES.

7 **SECTION 3.** In Colorado Revised Statutes, 25-4-1003, **amend**
8 (2) introductory portion and (2)(e) as follows:

9 **25-4-1003. Powers and duties of state board and executive**
10 **director - newborn screening programs - genetic counseling and**
11 **education programs - rules.** (2) The executive director of the
12 department of ~~public health and environment~~ shall comply with the
13 following provisions:

14 (e) All information gathered by the department of ~~public health~~
15 ~~and environment~~, or by other agencies, entities, and individuals
16 conducting programs and projects on newborn screening and genetic
17 counseling and education, other than statistical information and
18 information ~~which~~ THAT the ~~individual~~ PARENT OR GUARDIAN OF A
19 NEWBORN allows to be released through ~~his~~ THE PARENT'S OR GUARDIAN'S
20 informed consent, ~~shall be~~ IS confidential. Public and private access to
21 ~~individual~~ NEWBORN patient data ~~shall be~~ IS limited to data compiled
22 without the ~~individual's~~ NEWBORN'S name. THE INFORMATION GATHERED
23 PURSUANT TO THIS SUBSECTION (2)(e) DOES NOT RESTRICT THE
24 DEPARTMENT FROM PERFORMING FOLLOW-UP SERVICES WITH NEWBORNS,
25 THEIR PARENTS OR GUARDIANS, AND HEALTH CARE PROVIDERS.

26 **SECTION 4.** In Colorado Revised Statutes, 25-4-1004, **amend**
27 (1)(b), (1)(c) introductory portion, and (2); and **add** (1.5) as follows:

1 **25-4-1004. Newborn screening - advisory committee.**

2 (1) ~~(b) On or after April 1, 1989, all~~ Infants born in the state of Colorado
3 shall be tested for the following conditions: Phenylketonuria,
4 hypothyroidism, abnormal hemoglobins, galactosemia, cystic fibrosis,
5 biotinidase deficiency, and such other conditions as the STATE board of
6 health may determine meet the criteria set forth in ~~paragraph (c) of this~~
7 ~~subsection (1). Appropriate specimens for such testing shall be forwarded~~
8 ~~by the hospital in which the child is born to the laboratory operated or~~
9 ~~designated by the department of public health and environment for such~~
10 ~~purposes~~ SUBSECTION (1)(c) OF THIS SECTION. THE BIRTHING FACILITY
11 WHERE THE INFANT IS BORN SHALL FORWARD ALL APPROPRIATE
12 SPECIMENS TO THE LABORATORY OPERATED OR DESIGNATED BY THE
13 DEPARTMENT. The physician, nurse, midwife, or other health professional
14 attending a birth outside a ~~hospital shall be~~ BIRTHING FACILITY IS
15 responsible for ~~the collection~~ COLLECTING and forwarding of ~~such~~ THE
16 specimens. The LABORATORY SHALL FORWARD THE results of the testing
17 ~~shall be forwarded~~ directly to the physician, PRIMARY CARE PROVIDER, or
18 other ~~primary~~ health care provider AS NEEDED for the provision of such
19 information to the parent, ~~or~~ parents, OR GUARDIANS of the child. The
20 results of any testing or follow-up testing pursuant to section 25-4-1004.5
21 may be sent to the immunization tracking system authorized by section
22 25-4-2403 and accessed by the physician or other primary health care
23 provider. The state board of ~~health~~ may discontinue testing for any
24 condition listed in this ~~paragraph (b)~~ SUBSECTION (1)(b) if, upon
25 consideration of criteria set forth in ~~paragraph (c) of this subsection (1)~~
26 SUBSECTION (1)(c) OF THIS SECTION, the STATE board finds that the public
27 health is better served by not testing infants for that condition.

1 (c) The STATE board of ~~health~~ shall use the following criteria to
2 determine whether ~~or not~~ to test infants for conditions ~~which~~ THAT are not
3 specifically enumerated in this subsection (1):

4 (1.5) ON OR BEFORE SEPTEMBER 1, 2018, AND ON OR BEFORE
5 SEPTEMBER 1 EACH YEAR THEREAFTER, THE STATE BOARD SHALL ADD
6 NEW CONDITIONS FOR WHICH INFANTS MUST BE TESTED AS DEEMED
7 APPROPRIATE BY THE DEPARTMENT, BASED ON THE RECOMMENDED
8 UNIFORM SCREENING PANEL AS RECOMMENDED BY THE SECRETARY OF THE
9 UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES OR ITS
10 SUCCESSOR AGENCY.

11 (2) The executive director of the department of public health and
12 environment shall assess a fee ~~which~~ THAT is sufficient to cover the
13 DIRECT AND INDIRECT ONGOING costs of ~~such~~ THE testing REQUIRED BY
14 THIS SECTION and to accomplish the other purposes of this part 10.
15 ~~Hospitals shall~~ BIRTHING FACILITIES MAY assess a reasonable fee to be
16 charged the parent, ~~or~~ parents, OR GUARDIANS of the infant to cover the
17 costs of handling the specimens, the reimbursement of laboratory costs,
18 and the costs of providing other services, INCLUDING THE CONNECTION OF
19 FOLLOW-UP SERVICES AND CARE TO INFANTS IDENTIFIED AS AT RISK
20 THROUGH SCREENING, necessary to implement the purposes of this part
21 10.

22 **SECTION 5.** In Colorado Revised Statutes, 25-4-1004.5, **amend**
23 (2)(b), (3)(a) introductory portion, (3)(a)(V), (3)(b) introductory portion,
24 and (3)(c); **repeal** (1); and **add** (2)(c) and (3)(b.5) as follows:

25 **25-4-1004.5. Follow-up testing and treatment - second**
26 **screening - fee - rules.** (1) ~~The general assembly finds that:~~

27 (a) ~~Newborn screening authorized by section 25-4-1004 is~~

1 provided for every newborn in the state;

2 (b) ~~Newborn testing is designed to identify metabolic disorders~~
3 ~~that cause mental retardation and other health problems unless they are~~
4 ~~diagnosed and treated early in life;~~

5 (c) ~~In order to ensure that children with metabolic disorders are~~
6 ~~able to lead as normal a life as possible and to minimize long-term health~~
7 ~~care costs for such children, it is necessary to provide centralized~~
8 ~~follow-up testing and treatment services;~~

9 (d) ~~For over twenty-five years the follow-up testing and treatment~~
10 ~~services were provided by a federal grant that was discontinued June 30,~~
11 ~~1993. Since that time, follow-up testing and treatment services have been~~
12 ~~limited. If alternative sources of funding are not provided, those services~~
13 ~~will be eliminated.~~

14 (e) ~~A nominal increase of the fee on newborn screening to cover~~
15 ~~the costs of providing follow-up and referral services would allow for~~
16 ~~those services to be continued;~~

17 (f) ~~Over the past ten years, many children with serious health~~
18 ~~conditions have received timely diagnosis and treatment as a result of the~~
19 ~~newborn screening required by this part 10. Such screening has averted~~
20 ~~the possibility of life-long institutionalization of some children and~~
21 ~~substantial related health care costs. The general assembly further finds,~~
22 ~~however, that many infants who are screened early in life may exhibit~~
23 ~~false or inaccurate results on certain newborn screening tests. The general~~
24 ~~assembly therefore finds and declares that subsequent newborn screening~~
25 ~~will provide more accurate and reliable test results for the timely and~~
26 ~~effective diagnosis and treatment of certain health conditions in newborn~~
27 ~~infants and the best interests of children in Colorado will be served by a~~

1 ~~new screening program that routinely tests all newborns twice.~~

2 (2) (b) ~~On and after July 1, 1994,~~ The executive director of the
3 department of public health and environment shall increase the newborn
4 screening fee as provided in section 25-4-1004 (2) so that the fee is
5 sufficient to include the costs of providing FIRST AND SECOND SPECIMEN
6 TESTS WITH SECOND-TIER TESTING IF NECESSITATED BY THE RESULTS OF
7 THE SCREENING IN ORDER TO REDUCE THE NUMBER OF FALSE POSITIVE
8 TESTS AND TO PROVIDE follow-up and referral services to families with a
9 newborn whose test results under a newborn screening indicate a GENETIC
10 OR metabolic disorder. ~~Follow-up services include comprehensive~~
11 ~~diagnostic testing. The increase shall not exceed five dollars; except that~~
12 ~~it may be adjusted annually to reflect any change in the Denver-Boulder~~
13 ~~consumer price index. Any fees collected shall be subject to the~~
14 ~~provisions of section 25-4-1006.~~

15 (c) THE STATE BOARD SHALL PROMULGATE RULES TO ESTABLISH
16 AND MAINTAIN APPROPRIATE FOLLOW-UP SERVICES ON POSITIVE SCREEN
17 CASES IN ORDER THAT MEASURES MAY BE TAKEN TO PREVENT DEATH OR
18 INTELLECTUAL OR OTHER PERMANENT DISABILITIES. THE FOLLOW-UP
19 SERVICES MUST INCLUDE IDENTIFICATION OF NEWBORNS AT RISK FOR
20 GENETIC AND METABOLIC CONDITIONS, COORDINATION AMONG MEDICAL
21 PROVIDERS AND FAMILIES, CONNECTING NEWBORNS WHO SCREEN POSITIVE
22 TO TIMELY INTERVENTION AND APPROPRIATE REFERRALS TO SPECIALISTS
23 FOR FOLLOW-UP AND DIAGNOSTIC TESTING, AND ADDITIONAL DUTIES AS
24 DETERMINED BY THE DEPARTMENT.

25 (3) (a) ~~On and after July 1, 1996,~~ all Infants born in the state of
26 Colorado who receive newborn screening pursuant to section 25-4-1004
27 (1) ~~shall~~ MUST have a second specimen taken to screen for the following

1 conditions:

2 (V) Such other conditions as the state board of health may
3 determine meet the criteria set forth in section 25-4-1004 (1)(c) and
4 require a second screening for accurate test results.

5 (b) The executive director of the department of public health and
6 environment STATE BOARD is authorized to promulgate rules regulations,
7 and standards for the implementation of the second specimen testing
8 specified in this subsection (3), including: ~~but not limited to the~~
9 ~~following:~~

10 (b.5) THE LABORATORY OPERATED BY THE LABORATORY SERVICES
11 DIVISION IN THE DEPARTMENT, OR THE LABORATORY DESIGNATED BY THE
12 DEPARTMENT, AS APPLICABLE, MUST REMAIN OPEN A MINIMUM OF SIX
13 DAYS PER WEEK EVERY WEEK OF THE YEAR.

14 (c) On and after July 1, ~~1996~~ 2018, the executive director of the
15 department of public health and environment may adjust the newborn
16 screening fee set forth in section 25-4-1004 (2) so that the fee is sufficient
17 to cover the costs associated with the second screening described in this
18 subsection (3). ~~Any increase shall be in addition to the fee described in~~
19 ~~subsection (2) of this section and shall not initially exceed five dollars and~~
20 ~~seventy-five cents but may be adjusted annually to reflect any actual cost~~
21 ~~increase associated with the administration of the second screening. Any~~
22 ~~fees collected pursuant to this paragraph (c) shall be subject to the~~
23 ~~provisions of section 25-4-1006~~ MONEY IN THE NEWBORN SCREENING AND
24 GENETIC COUNSELING CASH FUNDS IS EXEMPT FROM SECTION 24-75-402.

25 **SECTION 6.** In Colorado Revised Statutes, 25-4-1004.7, **amend**
26 (2)(a)(I) introductory portion, (2)(a)(I)(A), (2)(a)(I)(C), (2)(a)(II), (3)(a),
27 and (5); **repeal** (1), (2)(a)(I)(B), (3)(b), and (4)(a); and **add** (7), (8), (9),

1 and (10) as follows:

2 **25-4-1004.7. Newborn hearing screening - advisory committee**

3 **- report - rules.** (1) ~~(a) The general assembly finds, determines, and~~
4 ~~declares:~~

5 ~~(I) That hearing loss occurs in newborn infants more frequently~~
6 ~~than any other health condition for which newborn infant screening is~~
7 ~~required;~~

8 ~~(II) That eighty percent of the language ability of a child is~~
9 ~~established by the time the child is eighteen months of age and that~~
10 ~~hearing is vitally important to the healthy development of such language~~
11 ~~skills;~~

12 ~~(III) That early detection of hearing loss in a child and early~~
13 ~~intervention and treatment has been demonstrated to be highly effective~~
14 ~~in facilitating a child's healthy development in a manner consistent with~~
15 ~~the child's age and cognitive ability;~~

16 ~~(IV) That children with hearing loss who do not receive such early~~
17 ~~intervention and treatment frequently require special educational services~~
18 ~~and that such services are publicly funded for the vast majority of~~
19 ~~children with hearing needs in the state;~~

20 ~~(V) That appropriate testing and identification of newborn infants~~
21 ~~with hearing loss will facilitate early intervention and treatment and may~~
22 ~~therefore serve the public purposes of promoting the healthy development~~
23 ~~of children and reducing public expenditure; and~~

24 ~~(VI) That consumers should be entitled to know whether the~~
25 ~~hospital at which they choose to deliver their infant provides newborn~~
26 ~~hearing screening.~~

27 (b) For these reasons the general assembly hereby determines that

1 it would be beneficial and in the best interests of the development of the
2 children of the state of Colorado that newborn infants' hearing be
3 screened.

4 (2) (a) (I) There is hereby established an advisory committee on
5 hearing in newborn infants for the purpose of collecting the informational
6 data specified in paragraph (b) of subsection (3) of this section, and for
7 the purpose of REVIEWING INFORMATION AND STATISTICS GATHERED
8 DURING THE NEWBORN HEARING SCREENING PROGRAM AND providing
9 recommendations to hospitals BIRTHING FACILITIES, other health care
10 institutions, the department, of public health and environment, and the
11 public concerning, but not necessarily limited to: the following:

12 (A) ~~Appropriate methodologies to be implemented~~ BEST
13 PRACTICES for hearing screening of newborn infants, which
14 ~~methodologies shall~~ PRACTICES MUST be objective and physiologically
15 based and ~~which shall~~ MUST not include a requirement that the initial
16 newborn hearing screening be performed by an audiologist; AND

17 (B) ~~The number of births sufficient to qualify a hospital or health~~
18 ~~institution to arrange otherwise for hearing screenings; and~~

19 (C) Guidelines AND BEST PRACTICES for reporting and the means
20 to assure that identified children receive referral for appropriate follow-up
21 services.

22 (II) The advisory committee on hearing in newborn infants shall
23 MUST consist of at least ~~seven~~ NINE members. ~~who shall be appointed by~~
24 The executive director of the department of public health and
25 environment SHALL APPOINT MEMBERS TO THE ADVISORY COMMITTEE.
26 Members appointed to the committee shall MUST have training,
27 experience, or interest in the area of hearing conditions LOSS in children

1 AND SHOULD INCLUDE REPRESENTATIVES FROM RURAL AND URBAN AREAS
2 OF THE STATE, A PARENT WHO HAS A CHILD WITH HEARING LOSS, A
3 REPRESENTATIVE OF A PATIENT AND FAMILY SUPPORT ORGANIZATION, A
4 REPRESENTATIVE OF A HOSPITAL, A REPRESENTATIVE FROM AN
5 ORGANIZATION REPRESENTING CULTURALLY DEAF PERSONS, AN
6 AMERICAN SIGN LANGUAGE EXPERT WHO HAS EXPERIENCE IN EVALUATION
7 AND INTERVENTION OF INFANTS AND YOUNG CHILDREN, AND PHYSICIANS
8 AND AUDIOLOGISTS WITH SPECIFIC EXPERTISE IN HEARING LOSS IN
9 INFANTS.

10 (3) (a) It is the intent of the general assembly that ~~newborn~~
11 ~~hearing screening be conducted on no fewer than ninety-five percent of~~
12 ~~the infants born in hospitals~~ INFANTS BORN IN THE STATE BE SCREENED
13 FOR HEARING LOSS using procedures recommended by the advisory
14 committee on hearing in newborn infants, created in subsection (2) of this
15 section. Toward that end, every licensed or certified ~~hospital~~ BIRTHING
16 FACILITY shall educate the parents of infants born in such ~~hospitals~~
17 BIRTHING FACILITIES of the importance of screening the hearing of
18 newborn infants and follow-up care. Education ~~shall not be~~ IS NOT
19 considered a substitute for the hearing screening described in this section.
20 Every ~~licensed or certified hospital~~ shall report annually to the advisory
21 committee concerning the following:

- 22 (I) ~~The number of infants born in the hospital;~~
23 (II) ~~The number of infants screened;~~
24 (III) ~~The number of infants who passed the screening, if~~
25 ~~administered; and~~
26 (IV) ~~The number of infants who did not pass the screening, if~~
27 ~~administered.~~

1 (b) ~~The advisory committee on hearing in newborn infants shall~~
2 ~~determine which hospitals or other health care institutions in the state of~~
3 ~~Colorado are administering hearing screening to newborn infants on a~~
4 ~~voluntary basis and the number of infants screened.~~

5 ~~(I) to (IV) Repealed.~~

6 (4) (a) ~~If the number of infants screened falls below eighty-five~~
7 ~~percent, the board of health shall promulgate rules requiring hearing~~
8 ~~screening of newborn infants pursuant to section 24-4-103, C.R.S., of the~~
9 ~~"State Administrative Procedure Act".~~

10 (5) A physician, nurse, midwife, or other health professional
11 attending a birth outside a hospital or institution shall ENSURE THAT THE
12 HEARING SCREENING IS PERFORMED WITHIN THIRTY DAYS OF THE BIRTH
13 AND SHALL provide information, as established by RULE OF the
14 department, to parents regarding ~~places where the parents may have their~~
15 ~~infants' hearing screened~~ and the importance of ~~such~~ THE screening. THE
16 PHYSICIAN, NURSE, MIDWIFE, OR OTHER HEALTH PROFESSIONAL SHALL
17 PROVIDE A REPORT OF ANY SCREENING TO THE PARENT OR GUARDIAN OF
18 THE INFANT, THE PRIMARY CARE PROVIDER OF THE INFANT, AND THE
19 DEPARTMENT.

20 (7) UPON RECEIPT OF SUFFICIENT FINANCIAL RESOURCES IN THE
21 NEWBORN HEARING SCREENING CASH FUND, AS DETERMINED BY THE
22 DEPARTMENT, TO SUPPORT A NEW INFORMATION TECHNOLOGY SYSTEM
23 FOR THE PURPOSE OF MANAGING THE NEWBORN HEARING SCREENING
24 PROGRAM, THE DEPARTMENT SHALL PROCURE AN INFORMATION
25 TECHNOLOGY SYSTEM AND PROMULGATE RULES IN ORDER TO IMPLEMENT
26 THE SYSTEM.

27 (8) (a) THE STATE BOARD OF HEALTH SHALL PROMULGATE RULES

1 THAT REQUIRE EACH OF THE FOLLOWING WITH INFORMATION PERTINENT
2 TO THIS SECTION TO REPORT THE RESULTS OF INDIVIDUAL SCREENING TO
3 THE DEPARTMENT:

4 (I) A BIRTHING FACILITY; OR

5 (II) ANOTHER FACILITY OR PROVIDER.

6 (b) THE RULES MUST INCLUDE A REQUIREMENT THAT THE BIRTHING
7 FACILITY INCLUDE THE RESULTS OF THE HEARING SCREENING IN THE
8 ELECTRONIC MEDICAL RECORD OF THE NEWBORN. THE INFORMATION
9 SYSTEM REQUIRED IN SUBSECTION (7) OF THIS SECTION MUST ALLOW THE
10 RESULTS OF OUTPATIENT RESCREENINGS TO BE REPORTED TO THE
11 DEPARTMENT AND TO THE PARENT OR GUARDIAN OF THE NEWBORN.

12 (9) (a) THE STATE BOARD OF HEALTH SHALL PROMULGATE RULES
13 TO ESTABLISH AND MAINTAIN APPROPRIATE FOLLOW-UP SERVICES FOR
14 NEWBORNS AT RISK OF HEARING LOSS AS WELL AS NEWBORNS WHO FAIL TO
15 RECEIVE SCREENING. THE FOLLOW-UP SERVICES MUST INCLUDE
16 IDENTIFICATION OF NEWBORNS AT RISK FOR HEARING LOSS, COORDINATION
17 AMONG MEDICAL AND AUDIOLOGY PROVIDERS AND FAMILIES, CONNECTING
18 NEWBORNS TO TIMELY INTERVENTION, APPROPRIATE REFERRALS TO
19 SPECIALISTS FOR FOLLOW-UP AND DIAGNOSTIC TESTING, AND ADDITIONAL
20 DUTIES AS DETERMINED BY THE DEPARTMENT.

21 (b) THE FOLLOW-UP SERVICES MUST PROVIDE THE PARENTS WITH
22 INFORMATION AND RESOURCES SO THAT THE PARENTS CAN, IN A TIMELY
23 MANNER, LOCATE APPROPRIATE DIAGNOSTIC AND TREATMENT SERVICES
24 FOR THE NEWBORN.

25 (c) THE DEPARTMENT SHALL ALSO PROVIDE APPROPRIATE
26 TRAINING, ON A PERIODIC BASIS, TO BIRTHING FACILITIES AND MIDWIVES
27 ON THE DEPARTMENT'S SCREENING PROGRAM.

1 (d) THE INFORMATION GATHERED BY THE DEPARTMENT, OTHER
2 THAN STATISTICAL INFORMATION AND INFORMATION THAT THE PARENT OR
3 GUARDIAN OF A NEWBORN ALLOWS TO BE RELEASED THROUGH THE
4 PARENT'S OR GUARDIAN'S INFORMED CONSENT, IS CONFIDENTIAL. PUBLIC
5 ACCESS TO NEWBORN PATIENT DATA IS LIMITED TO DATA COMPILED
6 WITHOUT THE NEWBORN'S NAME. AUDIOLOGISTS AND OTHER HEALTH
7 PROFESSIONALS PROVIDING DIAGNOSTIC SERVICES TO NEWBORNS AND
8 THEIR FAMILIES MAY ACCESS THE INFORMATION, ON A NEWBORN-SPECIFIC
9 BASIS, FOR THE PURPOSE OF ENTERING FOLLOW-UP INFORMATION. THE
10 INFORMATION GATHERED IN ACCORDANCE WITH THIS SUBSECTION (9)(d)
11 DOES NOT RESTRICT THE DEPARTMENT FROM PERFORMING FOLLOW-UP
12 SERVICES WITH NEWBORNS, THEIR PARENTS OR GUARDIANS, AND HEALTH
13 CARE PROVIDERS.

14 (10) THE EXECUTIVE DIRECTOR OF THE DEPARTMENT MAY ASSESS
15 A FEE THAT IS SUFFICIENT TO COVER THE ONGOING DIRECT AND INDIRECT
16 COSTS OF ALL INITIAL NEWBORN HEARING SCREENING AND FOLLOW-UP
17 SERVICES AND TO ACCOMPLISH THE OTHER PURPOSES OF THIS SECTION,
18 WHICH FEE SHALL BE DEPOSITED INTO THE NEWBORN HEARING SCREENING
19 CASH FUND CREATED IN SECTION 25-4-1006(3). BIRTHING FACILITIES MAY
20 ASSESS A REASONABLE FEE TO BE CHARGED THE PARENT OR GUARDIAN OF
21 THE NEWBORN TO COVER THE COSTS OF PROVIDING SERVICES NECESSARY
22 TO IMPLEMENT THE PURPOSES OF THIS SECTION.

23 **SECTION 7.** In Colorado Revised Statutes, 25-4-1006, **amend**
24 (1); and **add** (3) and (4) as follows:

25 **25-4-1006. Cash funds.** (1) All ~~moneys~~ MONEY received from
26 fees collected pursuant to this part 10, EXCEPT FOR THE MONEY RECEIVED
27 PURSUANT TO SECTION 25-4-1004.7, shall be transmitted to the state

1 treasurer, who shall credit ~~the same~~ IT to the newborn screening and
2 genetic counseling cash funds, which funds are hereby created. Such
3 ~~moneys~~ MONEY shall be utilized for expenditures authorized or
4 contemplated by and not inconsistent with the provisions of this part 10
5 relating to newborn screening, follow-up care, and genetic counseling and
6 education programs and functions. All ~~moneys~~ MONEY credited to the
7 newborn screening and genetic counseling cash funds shall be used as
8 provided in this part 10 and shall not be deposited in or transferred to the
9 general fund of this state or any other fund.

10 (3) THERE IS HEREBY CREATED THE NEWBORN HEARING
11 SCREENING CASH FUND FOR THE PURPOSE OF COVERING THE ONGOING
12 DIRECT AND INDIRECT COSTS ASSOCIATED WITH THE ADMINISTRATION OF
13 THE NEWBORN HEARING SCREENING PROGRAM. ALL MONEY COLLECTED
14 PURSUANT TO SECTION 25-4-1004.7 SHALL BE TRANSMITTED TO THE STATE
15 TREASURER, WHO SHALL CREDIT IT TO THE NEWBORN HEARING SCREENING
16 CASH FUND. THE MONEY IN THE CASH FUND AT THE END OF ANY FISCAL
17 YEAR SHALL REMAIN IN THE CASH FUND AND SHALL NOT BE CREDITED OR
18 TRANSFERRED TO THE GENERAL FUND OR ANY OTHER FUND. IN ADDITION,
19 THE GENERAL ASSEMBLY MAY APPROPRIATE MONEY FROM THE GENERAL
20 FUND TO THE DEPARTMENT TO IMPLEMENT THE NEWBORN HEARING
21 SCREENING PROGRAM.

22 (4) MONEY IN THE NEWBORN SCREENING AND GENETIC
23 COUNSELING CASH FUNDS AND THE NEWBORN HEARING SCREENING CASH
24 FUND ARE EXEMPT FROM SECTION 24-75-402.

25 **SECTION 8.** In Colorado Revised Statutes, **add** 25-4-1002.5 as
26 follows:

27 **25-4-1002.5. Definitions.** AS USED IN THIS PART 10, UNLESS THE

1 CONTEXT OTHERWISE REQUIRES:

2 (1) "BIRTHING FACILITY" MEANS A GENERAL HOSPITAL OR
3 BIRTHING CENTER LICENSED OR CERTIFIED PURSUANT TO SECTION
4 25-1.5-103.

5 (2) "DEPARTMENT" MEANS THE DEPARTMENT OF PUBLIC HEALTH
6 AND ENVIRONMENT.

7 (3) "STATE BOARD" MEANS THE STATE BOARD OF HEALTH IN THE
8 DEPARTMENT.

9 **SECTION 9.** In Colorado Revised Statutes, 24-75-302, **amend**
10 **as added by House Bill 18-1173** (2.3)(c) and (2.3)(d); and **add** (2.3)(e)
11 **as follows:**

12 **24-75-302. Capital construction fund - capital assessment fees**
13 **- calculation - information technology capital account.** (2.3) In
14 addition to the sums transferred pursuant to subsections (2) and (2.5) of
15 this section, the state treasurer and the controller shall transfer a sum as
16 specified in this subsection (2.3) from the general fund to the information
17 technology capital account created in subsection (3.7) of this section, as
18 enacted by House Bill 15-1266, as money becomes available in the
19 general fund during the fiscal year beginning on July 1 of the fiscal year
20 in which the transfer is made. Transfers between funds pursuant to this
21 subsection (2.3) are not appropriations subject to the limitations of section
22 24-75-201.1. The amounts transferred pursuant to this subsection (2.3) are
23 **as follows:**

24 (c) On July 1, 2017, nineteen million eight hundred fifty-five
25 thousand five hundred fifteen dollars; **and**

26 (d) On April 1, 2018, two million eight hundred eighty-eight
27 thousand five hundred twenty-nine dollars; **AND**

1 (e) ON JULY 1, 2018, SEVEN HUNDRED THOUSAND DOLLARS.

2 **SECTION 10. Capital construction appropriation.** (1) For the
3 2018-19 state fiscal year, \$700,000 is appropriated to the department of
4 public health and environment for use by the center for health and
5 environmental information. This appropriation is from reappropriated
6 funds in the information technology capital account within the capital
7 construction fund created in section 24-75-302 (3.7), C.R.S. To
8 implement this act, the center may use this appropriation for capital
9 construction related to an information technology system for hearing loss
10 screening. Any money appropriated in this subsection (1) not expended
11 prior to July 1, 2019, is further appropriated to the division for the
12 2019-20 and 2020-21 state fiscal years for the same purpose.

13 (2) For the 2018-19 state fiscal year, \$642,500 is appropriated to
14 the department of public health and environment for use by the laboratory
15 services division. This appropriation is from the newborn screening and
16 genetic counseling cash funds created in section 25-4-1006 (1), C.R.S. To
17 implement this act, the division may use this appropriation for capital
18 construction related to laboratory space expansion. Any money
19 appropriated in this subsection (2) not expended prior to July 1, 2019, is
20 further appropriated to the division for the 2019-20 and 2020-21 state
21 fiscal years for the same purpose.

22 **SECTION 11. Appropriation.** (1) For the 2018-19 state fiscal
23 year, \$89,222 is appropriated to the department of public health and
24 environment for use by the center for health and environmental
25 information. This appropriation is from the newborn hearing screening
26 cash fund created in section 25-4-1006 (3), C.R.S., and is based on the
27 assumption that the center will require an additional 1.0 FTE. To

1 implement this act, the center may use this appropriation the birth defects
2 monitoring and prevention program.

3 (2) For the 2018-19 state fiscal year, \$520,000 is appropriated to
4 the department of public health and environment for use by the laboratory
5 services division. This appropriation is from the newborn screening and
6 genetic counseling cash funds created in section 25-4-1006 (1), C.R.S. To
7 implement this act, the division may use this appropriation for chemistry
8 and microbiology operating expenses.

9 **SECTION 12. Effective date.** This act takes effect July 1, 2018.

10 **SECTION 13. Safety clause.** The general assembly hereby finds,
11 determines, and declares that this act is necessary for the immediate
12 preservation of the public peace, health, and safety.