# Second Regular Session Seventy-first General Assembly STATE OF COLORADO

## REENGROSSED

This Version Includes All Amendments Adopted in the House of Introduction

LLS NO. 18-0435.01 Kristen Forrestal x4217

**HOUSE BILL 18-1006** 

### **HOUSE SPONSORSHIP**

Hamner and Liston,

## SENATE SPONSORSHIP

Gardner and Moreno,

#### **House Committees**

### **Senate Committees**

Public Health Care & Human Services Finance Appropriations

### 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 <a href="http://leg.colorado.gov">http://leg.colorado.gov</a>.)

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 HOUSE 3rd Reading Unamended April 20, 2018

HOUSE Amended 2nd Reading April 19, 2018 necessary follow-up services. The bill creates the newborn hearing screening cash fund for the purpose of covering the costs of the program.

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

1

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	<b>25-4-1002.</b> 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;

-2-

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 NEWBORN SCREENING
11	PROGRAMS OR genetic counseling programs in this state should be wholly
12	voluntary and that all information obtained from persons involved in such
13	programs or in newborn screening programs in the state should be held
14	strictly confidential. FAMILY PARTICIPATION IN THE FOLLOW-UP SUPPORT
15	AND ASSISTANCE SERVICES IS VOLUNTARY.
16	(i) Hearing loss occurs in Newborn infants more
17	FREQUENTLY THAN ANY OTHER HEALTH CONDITION FOR WHICH NEWBORN
18	INFANT SCREENING IS REQUIRED;
19	(j) EIGHTY PERCENT OF THE LANGUAGE ABILITY OF A CHILD IS
20	ESTABLISHED BY THE TIME THE CHILD IS EIGHTEEN MONTHS OF AGE, AND
21	IT IS VITALLY IMPORTANT TO SUPPORT THE HEALTHY DEVELOPMENT OF
22	LANGUAGE SKILLS;
23	(k) EARLY DETECTION, EARLY INTERVENTION, AND TREATMENT OF
24	HEARING LOSS IN A CHILD ARE HIGHLY EFFECTIVE IN FACILITATING A
25	CHILD'S HEALTHY DEVELOPMENT IN A MANNER CONSISTENT WITH THE
26	CHILD'S AGE AND COGNITIVE ABILITY;
27	(1) CHILDREN WITH HEARING LOSS WHO DO NOT RECEIVE EARLY

-3-

1	INTERVENTION AND TREATMENT FREQUENTLY REQUIRE SPECIAL
2	EDUCATIONAL SERVICES, WHICH, FOR THE VAST MAJORITY OF CHILDREN
3	IN THE STATE WITH HEARING NEEDS, ARE PUBLICLY FUNDED; AND
4	(m) APPROPRIATE TESTING AND IDENTIFICATION OF NEWBORN
5	INFANTS WITH HEARING LOSS WILL FACILITATE EARLY INTERVENTION AND
6	TREATMENT AND WILL THEREFORE SERVE THE PUBLIC PURPOSES OF
7	PROMOTING THE HEALTHY DEVELOPMENT OF CHILDREN AND REDUCING
8	THE NEED FOR ADDITIONAL PUBLIC EXPENDITURES.
9	SECTION 3. In Colorado Revised Statutes, 25-4-1003, amend
10	(2) introductory portion and (2)(e) as follows:
11	25-4-1003. Powers and duties of state board and executive
12	director - newborn screening programs - genetic counseling and
13	education programs - rules. (2) The executive director of the
14	department of public health and environment shall comply with the
15	following provisions:
16	(e) All information gathered by the department of public health
17	and environment, or by other agencies, entities, and individuals
18	conducting programs and projects on newborn screening and genetic
19	counseling and education, other than statistical information and
20	information which THAT the individual PARENT OR GUARDIAN OF A
21	NEWBORN allows to be released through his THE PARENT'S OR GUARDIAN'S
22	informed consent, shall be IS confidential. Public and private access to
23	individual NEWBORN patient data shall be IS limited to data compiled
24	without the individual's NEWBORN'S name. THE INFORMATION GATHERED
25	PURSUANT TO THIS SUBSECTION (2)(e) DOES NOT RESTRICT THE
26	DEPARTMENT FROM PERFORMING FOLLOW-UP SERVICES WITH NEWBORNS,
27	THEIR PARENTS OR CHARDIANS AND HEATTH CARE PROVIDERS

-4- 1006

1 **SECTION 4.** In Colorado Revised Statutes, 25-4-1004, amend 2 (1)(b), (1)(c) introductory portion, and (2); and add (1.5) and (3) as 3 follows: 4 25-4-1004. Newborn screening - advisory committee - rules. 5 (1) (b) On or after April 1, 1989, all Infants born in the state of Colorado 6 shall be tested for the following conditions: Phenylketonuria, 7 hypothyroidism, abnormal hemoglobins, galactosemia, cystic fibrosis, 8 biotinidase deficiency, and such other conditions as the STATE board of 9 health may determine meet the criteria set forth in paragraph (c) of this 10 subsection (1). Appropriate specimens for such testing shall be forwarded 11 by the hospital in which the child is born to the laboratory operated or 12 designated by the department of public health and environment for such 13 purposes SUBSECTION (1)(c) OF THIS SECTION. THE BIRTHING FACILITY 14 WHERE THE INFANT IS BORN SHALL FORWARD ALL APPROPRIATE 15 SPECIMENS TO THE LABORATORY OPERATED OR DESIGNATED BY THE 16 DEPARTMENT. The physician, nurse, midwife, or other health professional 17 attending a birth outside a hospital shall be BIRTHING FACILITY IS 18 responsible for the collection COLLECTING and forwarding of such THE 19 specimens. The LABORATORY SHALL FORWARD THE results of the testing 20 shall be forwarded directly to the physician, PRIMARY CARE PROVIDER, or 21 other primary health care provider AS NEEDED for the provision of such 22 information to the parent, or parents, OR GUARDIANS of the child. The 23 results of any testing or follow-up testing pursuant to section 25-4-1004.5 24 may be sent to the immunization tracking system authorized by section

25-4-2403 and accessed by the physician or other primary health care

provider. The state board of health may discontinue testing for any

condition listed in this paragraph (b) SUBSECTION (1)(b) if, upon

25

26

27

-5- 1006

consideration of criteria set forth in paragraph (c) of this subsection (1) SUBSECTION (1)(c) OF THIS SECTION, the STATE board finds that the public health is better served by not testing infants for that condition.

1

2

3

4

5

6

11

14

15

16

17

18

19

20

21

22

23

24

25

26

27

- (c) The STATE board of health shall use the following criteria to determine whether or not to test infants for conditions which THAT are not specifically enumerated in this subsection (1):
- 7 (1.5) On or before September 1, 2018, and on or before 8 SEPTEMBER 1 EACH YEAR THEREAFTER, THE STATE BOARD SHALL ADD 9 NEW CONDITIONS FOR WHICH INFANTS MUST BE TESTED AS DEEMED 10 APPROPRIATE BY THE DEPARTMENT, BASED ON THE RECOMMENDED UNIFORM SCREENING PANEL AS RECOMMENDED BY THE SECRETARY OF THE 12 UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES OR ITS 13 SUCCESSOR AGENCY.
  - (2) The executive director of the department of public health and environment shall assess a fee which THAT is sufficient to cover the DIRECT AND INDIRECT costs of such THE testing REQUIRED BY THIS SECTION and to accomplish the other purposes of this part 10. Hospitals shall BIRTHING FACILITIES MAY assess a reasonable fee to be charged the parent, or parents, OR GUARDIANS of the infant to cover the costs of handling the specimens, the reimbursement of laboratory costs, and the costs of providing other services, INCLUDING THE CONNECTION OF FOLLOW-UP SERVICES AND CARE TO INFANTS IDENTIFIED AS AT RISK THROUGH SCREENING, necessary to implement the purposes of this part 10.
  - (3) THE STATE BOARD SHALL PROMULGATE RULES CONCERNING THE REQUIREMENTS OF THE NEWBORN SCREENING PROGRAM FOR GENETIC AND METABOLIC DISORDERS, INCLUDING:

1006 -6-

1	(1) IN ADDITION TO THOSE CONDITIONS LISTED IN SUBSECTION
2	(1)(b) OF THIS SECTION, ANY OTHER CONDITIONS FOR WHICH TESTING
3	MUST OCCUR;
4	(II) OBTAINING SAMPLES OR SPECIMENS FROM NEWBORN INFANTS
5	REQUIRED FOR THE TESTS PRESCRIBED BY THE STATE BOARD; AND
6	(III) THE HANDLING AND DELIVERY OF SAMPLES OR SPECIMENS FOR
7	TESTING AND EXAMINATION.
8	SECTION 5. In Colorado Revised Statutes, 25-4-1004.5, amend
9	(2)(b), (3)(a) introductory portion, (3)(a)(V), (3)(b) introductory portion,
10	and (3)(c); <b>repeal</b> (1); and <b>add</b> (2)(c) and (3)(b.5) as follows:
11	25-4-1004.5. Follow-up testing and treatment - second
12	screening - fee - rules. (1) The general assembly finds that:
13	(a) Newborn screening authorized by section 25-4-1004 is
14	provided for every newborn in the state;
15	(b) Newborn testing is designed to identify metabolic disorders
16	that cause mental retardation and other health problems unless they are
17	diagnosed and treated early in life;
18	(c) In order to ensure that children with metabolic disorders are
19	able to lead as normal a life as possible and to minimize long-term health
20	care costs for such children, it is necessary to provide centralized
21	follow-up testing and treatment services;
22	(d) For over twenty-five years the follow-up testing and treatment
23	services were provided by a federal grant that was discontinued June 30,
24	1993. Since that time, follow-up testing and treatment services have been
25	limited. If alternative sources of funding are not provided, those services
26	will be eliminated.
2.7	(e) A nominal increase of the fee on newborn screening to cover

-7- 1006

the costs of providing follow-up and referral services would allow for those services to be continued;

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

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

-8- 1006

1	(c) THE STATE BOARD SHALL PROMULGATE RULES TO ESTABLISH
2	AND MAINTAIN APPROPRIATE FOLLOW-UP SERVICES ON POSITIVE SCREEN
3	CASES IN ORDER THAT MEASURES MAY BE TAKEN TO PREVENT DEATH OR
4	INTELLECTUAL OR OTHER PERMANENT DISABILITIES. THE FOLLOW-UP
5	SERVICES MUST INCLUDE IDENTIFICATION OF NEWBORNS AT RISK FOR
6	GENETIC AND METABOLIC CONDITIONS, COORDINATION AMONG MEDICAL
7	PROVIDERS AND FAMILIES, CONNECTING NEWBORNS WHO SCREEN POSITIVE
8	TO TIMELY INTERVENTION AND APPROPRIATE REFERRALS TO SPECIALISTS
9	FOR FOLLOW-UP AND DIAGNOSTIC TESTING, AND ADDITIONAL DUTIES AS
10	DETERMINED BY THE DEPARTMENT.
11	(3) (a) On and after July 1, 1996, all Infants born in the state of
12	Colorado who receive newborn screening pursuant to section 25-4-1004
13	(1) shall MUST have a second specimen taken to screen for the following
14	conditions:
15	(V) Such other conditions as the state board of health may
16	determine meet the criteria set forth in section 25-4-1004 (1)(c) and
17	require a second screening for accurate test results.
18	(b) The executive director of the department of public health and
19	environment STATE BOARD is authorized to promulgate rules regulations,
20	and standards for the implementation of the second specimen testing
21	specified in this subsection (3), including: but not limited to the
22	following:
23	$(b.5)\ The \ Laboratory\ operated\ by\ the\ Laboratory\ services$
24	DIVISION IN THE DEPARTMENT, OR THE LABORATORY DESIGNATED BY THE
25	DEPARTMENT, AS APPLICABLE, MUST REMAIN OPEN A MINIMUM OF SIX
26	DAYS PER WEEK EVERY WEEK OF THE YEAR.
27	(c) On and after July 1 1996 2018, the executive director of the

-9- 1006

1	department of public health and environment may adjust the newborn
2	screening fee set forth in section 25-4-1004 (2) so that the fee is sufficient
3	to cover the costs associated with the second screening described in this
4	subsection (3). Any increase shall be in addition to the fee described in
5	subsection (2) of this section and shall not initially exceed five dollars and
6	seventy-five cents but may be adjusted annually to reflect any actual cost
7	increase associated with the administration of the second screening. Any
8	fees collected pursuant to this paragraph (c) shall be subject to the
9	provisions of section 25-4-1006 MONEY IN THE NEWBORN SCREENING AND
10	GENETIC COUNSELING CASH FUNDS IS EXEMPT FROM SECTION 24-75-402.
11	SECTION 6. In Colorado Revised Statutes, 25-4-1004.7, amend
12	(2)(a)(I) introductory portion, $(2)(a)(I)(A)$ , $(2)(a)(I)(C)$ , $(2)(a)(II)$ , $(3)(a)$ ,
13	and (5); <b>repeal</b> (1), (2)(a)(I)(B), (3)(b), and (4)(a); and <b>add</b> (7), (8), (9),
14	(10), and (11) as follows:
15	25-4-1004.7. Newborn hearing screening - advisory committee
16	- report - rules. (1) (a) The general assembly finds, determines, and
17	<del>declares:</del>
18	(I) That hearing loss occurs in newborn infants more frequently
19	than any other health condition for which newborn infant screening is
20	required;
21	(II) That eighty percent of the language ability of a child is
22	established by the time the child is eighteen months of age and that
23	hearing is vitally important to the healthy development of such language
24	<del>skills;</del>
25	(III) That early detection of hearing loss in a child and early
26	intervention and treatment has been demonstrated to be highly effective
27	in facilitating a child's healthy development in a manner consistent with

-10-

the child's age and cognitive ability;
(IV) That children with hearing loss who do not receive such early
intervention and treatment frequently require special educational services
and that such services are publicly funded for the vast majority of
children with hearing needs in the state;
(V) That appropriate testing and identification of newborn infants
with hearing loss will facilitate early intervention and treatment and may
therefore serve the public purposes of promoting the healthy development
of children and reducing public expenditure; and
(VI) That consumers should be entitled to know whether the
hospital at which they choose to deliver their infant provides newborn
hearing screening.
(b) For these reasons the general assembly hereby determines that
it would be beneficial and in the best interests of the development of the
children of the state of Colorado that newborn infants' hearing be
screened.
(2) (a) (I) There is hereby established an advisory committee on
hearing in newborn infants for the purpose of collecting the informational
data specified in paragraph (b) of subsection (3) of this section, and for
the purpose of REVIEWING INFORMATION AND STATISTICS GATHERED
DURING THE NEWBORN HEARING SCREENING PROGRAM AND providing
recommendations to hospitals BIRTHING FACILITIES, other health care
institutions, the department, of public health and environment, and the
public concerning, but not necessarily limited to: the following:
(A) Appropriate methodologies to be implemented BEST

PRACTICES for hearing screening of newborn infants, which

methodologies shall PRACTICES MUST be objective and physiologically

-11- 1006

based and which shall MUST not include a requirement that the initial newborn hearing screening be performed by an audiologist; AND

- (B) The number of births sufficient to qualify a hospital or health institution to arrange otherwise for hearing screenings; and
- (C) Guidelines AND BEST PRACTICES for reporting and the means to assure that identified children receive referral for appropriate follow-up services.
- (II) The advisory committee on hearing in newborn infants shall MUST consist of at least seven NINE members. Who shall be appointed by The executive director of the department of public health and environment SHALL APPOINT MEMBERS TO THE ADVISORY COMMITTEE. Members appointed to the committee shall MUST have training, experience, or interest in the area of hearing conditions Loss in children AND SHOULD INCLUDE REPRESENTATIVES FROM RURAL AND URBAN AREAS OF THE STATE, A PARENT WHO HAS A CHILD WITH HEARING LOSS, A REPRESENTATIVE OF A PATIENT AND FAMILY SUPPORT ORGANIZATION, A REPRESENTATIVE OF A HOSPITAL, A REPRESENTATIVE FROM AN ORGANIZATION REPRESENTING CULTURALLY DEAF PERSONS, AN AMERICAN SIGN LANGUAGE EXPERT WHO HAS EXPERIENCE IN EVALUATION AND INTERVENTION OF INFANTS AND YOUNG CHILDREN, AND PHYSICIANS AND AUDIOLOGISTS WITH SPECIFIC EXPERTISE IN HEARING LOSS IN INFANTS.
- (3) (a) It is the intent of the general assembly that newborn hearing screening be conducted on no fewer than ninety-five percent of the infants born in hospitals INFANTS BORN IN THE STATE BE SCREENED FOR HEARING LOSS using procedures recommended by the advisory committee on hearing in newborn infants, created in subsection (2) of this

-12- 1006

1	section. Toward that end, every licensed or certified hospital BIRTHING
2	FACILITY shall educate the parents of infants born in such hospitals
3	BIRTHING FACILITIES of the importance of screening the hearing of
4	newborn infants and follow-up care. Education shall not be IS NOT
5	considered a substitute for the hearing screening described in this section.
6	Every licensed or certified hospital shall report annually to the advisory
7	committee concerning the following:
8	(I) The number of infants born in the hospital;
9	(II) The number of infants screened;
10	(III) The number of infants who passed the screening, if
11	administered; and
12	(IV) The number of infants who did not pass the screening, if
13	administered.
14	(b) The advisory committee on hearing in newborn infants shall
15	determine which hospitals or other health care institutions in the state of
16	Colorado are administering hearing screening to newborn infants on a
17	voluntary basis and the number of infants screened.
18	(I) to (IV) Repealed.
19	(4) (a) If the number of infants screened falls below eighty-five
20	percent, the board of health shall promulgate rules requiring hearing
21	screening of newborn infants pursuant to section 24-4-103, C.R.S., of the
22	"State Administrative Procedure Act".
23	(5) A physician, nurse, midwife, or other health professional
24	attending a birth outside a hospital or institution shall MAKE EVERY
25	PROFESSIONAL EFFORT, AS DEFINED BY THE BOARD, INCLUDING
26	FOLLOWING UP AT SCHEDULED POSTPARTUM APPOINTMENTS, TO ENSURE
27	THAT THE HEARING SCREENING IS PERFORMED WITHIN THIRTY DAYS OF

-13-

1	THE BIRTH AND SHALL provide information, as established by RULE OF the
2	department, to parents regarding places where the parents may have their
3	infants' hearing screened and the importance of such THE screening. THE
4	PHYSICIAN, NURSE, MIDWIFE, OR OTHER HEALTH PROFESSIONAL WHO
5	PERFORMS THE SCREENING SHALL PROVIDE A REPORT OF ANY SCREENING
6	TO THE PARENT OR GUARDIAN OF THE INFANT, THE PRIMARY CARE
7	PROVIDER OF THE INFANT, AND THE DEPARTMENT.
8	(7) Upon receipt of sufficient financial resources in the
9	NEWBORN HEARING SCREENING CASH FUND, AS DETERMINED BY THE
10	DEPARTMENT, TO SUPPORT A NEW INFORMATION TECHNOLOGY SYSTEM
11	FOR THE PURPOSE OF MANAGING THE NEWBORN HEARING SCREENING
12	PROGRAM, THE DEPARTMENT SHALL PROCURE AN INFORMATION
13	TECHNOLOGY SYSTEM AND PROMULGATE RULES IN ORDER TO IMPLEMENT
14	THE SYSTEM.
15	(8) (a) THE STATE BOARD OF HEALTH SHALL PROMULGATE RULES
16	THAT REQUIRE EACH OF THE FOLLOWING WITH INFORMATION PERTINENT
17	TO THIS SECTION TO REPORT THE RESULTS OF INDIVIDUAL SCREENING TO
18	THE DEPARTMENT:
19	(I) A BIRTHING FACILITY; OR
20	(II) ANOTHER FACILITY OR PROVIDER.
21	(b) THE RULES MUST INCLUDE A REQUIREMENT THAT THE BIRTHING
22	FACILITY INCLUDE THE RESULTS OF THE HEARING SCREENING IN THE
23	ELECTRONIC MEDICAL RECORD OF THE NEWBORN. THE INFORMATION
24	SYSTEM REQUIRED IN SUBSECTION (7) OF THIS SECTION MUST ALLOW THE
25	RESULTS OF OUTPATIENT RESCREENINGS TO BE REPORTED TO THE
26	DEPARTMENT AND TO THE PARENT OR GUARDIAN OF THE NEWBORN.
27	(9) (a) THE STATE BOARD OF HEALTH SHALL PROMULGATE RULES

-14- 1006

1	TO ESTABLISH AND MAINTAIN APPROPRIATE FOLLOW-UP SERVICES FOR
2	NEWBORNS AT RISK OF HEARING LOSS AS WELL AS NEWBORNS WHO FAIL TO
3	RECEIVE SCREENING. THE FOLLOW-UP SERVICES MUST INCLUDE
4	IDENTIFICATION OF NEWBORNS AT RISK FOR HEARING LOSS, COORDINATION
5	AMONG MEDICAL AND AUDIOLOGY PROVIDERS AND FAMILIES, CONNECTING
6	NEWBORNS TO TIMELY INTERVENTION, APPROPRIATE REFERRALS TO
7	SPECIALISTS FOR FOLLOW-UP AND DIAGNOSTIC TESTING, AND ADDITIONAL
8	DUTIES AS DETERMINED BY THE DEPARTMENT.
9	(b) THE FOLLOW-UP SERVICES MUST PROVIDE THE PARENTS WITH
10	INFORMATION AND RESOURCES SO THAT THE PARENTS CAN, IN A TIMELY
11	MANNER, LOCATE APPROPRIATE DIAGNOSTIC AND TREATMENT SERVICES
12	FOR THE NEWBORN.
13	(c) The department shall also provide appropriate
14	TRAINING, ON A PERIODIC BASIS, TO BIRTHING FACILITIES AND MIDWIVES
15	ON THE DEPARTMENT'S SCREENING PROGRAM.
16	(d) THE INFORMATION GATHERED BY THE DEPARTMENT, OTHER
17	THAN STATISTICAL INFORMATION AND INFORMATION THAT THE PARENT OR
18	GUARDIAN OF A NEWBORN ALLOWS TO BE RELEASED THROUGH THE
19	PARENT'S OR GUARDIAN'S INFORMED CONSENT, IS CONFIDENTIAL. PUBLIC
20	ACCESS TO NEWBORN PATIENT DATA IS LIMITED TO DATA COMPILED
21	WITHOUT THE NEWBORN'S NAME. AUDIOLOGISTS AND OTHER HEALTH
22	PROFESSIONALS PROVIDING DIAGNOSTIC SERVICES TO NEWBORNS AND
23	THEIR FAMILIES MAY ACCESS THE INFORMATION, ON A NEWBORN-SPECIFIC
24	BASIS, FOR THE PURPOSE OF ENTERING FOLLOW-UP INFORMATION. THE
25	INFORMATION GATHERED IN ACCORDANCE WITH THIS SUBSECTION (9)(d)
26	DOES NOT RESTRICT THE DEPARTMENT FROM PERFORMING FOLLOW-UP
27	SERVICES WITH NEWBORNS, THEIR PARENTS OR GUARDIANS, AND HEALTH

-15- 1006

1	CARE PROVIDERS.
2	(10) (a) The department shall develop and publish
3	MATERIALS ON ITS WEBSITE FOR USE IN EDUCATING AND TRAINING ON
4	CYTOMEGALOVIRUS, REFERRED TO AS "CMV", THAT INCLUDE THE
5	FOLLOWING:
6	(I) THE ESTIMATED INCIDENCE OF CMV;
7	(II) THE TRANSMISSION OF CMV TO PREGNANT WOMEN OR WOMEN
8	WHO MAY BECOME PREGNANT;
9	(III) BIRTH DEFECTS CAUSED BY CONGENITAL CMV;
10	(IV) METHODS OF DIAGNOSING CONGENITAL CMV;
11	(V) AVAILABLE PREVENTIVE MEASURES TO AVOID THE INFECTION
12	IN WOMEN WHO ARE PREGNANT OR MAY BECOME PREGNANT;
13	(VI) RESOURCES AND EVIDENCE-BASED TREATMENT AS THEY
14	BECOME AVAILABLE FOR FAMILIES OF CHILDREN BORN WITH CMV; AND
15	(VII) ANY FEDERAL OR STATE REQUIREMENTS REGARDING
16	TESTING FOR CMV.
17	(b) SUBJECT TO AVAILABLE APPROPRIATIONS, THE DEPARTMENT
18	SHALL PROVIDE TECHNICAL ASSISTANCE AND TRAINING REGARDING CMV
19	TO HEALTH CARE FACILITIES AND HEALTH CARE PROVIDERS UPON
20	REQUEST.
21	(11) THE EXECUTIVE DIRECTOR OF THE DEPARTMENT MAY ASSESS
22	A FEE THAT IS SUFFICIENT TO COVER THE ONGOING DIRECT AND INDIRECT
23	COSTS OF ALL INITIAL NEWBORN HEARING SCREENING AND FOLLOW-UP
24	SERVICES AND TO ACCOMPLISH THE OTHER PURPOSES OF THIS SECTION.
25	WHICH FEE SHALL BE DEPOSITED INTO THE NEWBORN HEARING SCREENING
26	CASH FUND CREATED IN SECTION 25-4-1006(3). BIRTHING FACILITIES MAY
27	ASSESS A REASONABLE FEE TO BE CHARGED THE PARENT OR GUARDIAN OF

-16- 1006

1	THE NEWBORN TO COVER THE COSTS OF PROVIDING SERVICES NECESSARY
2	TO IMPLEMENT THE PURPOSES OF THIS SECTION.

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

25-4-1006. Cash funds. (1) All moneys MONEY received from fees collected pursuant to this part 10, EXCEPT FOR THE MONEY RECEIVED PURSUANT TO SECTION 25-4-1004.7, shall be transmitted to the state treasurer, who shall credit the same IT to the newborn screening and genetic counseling cash funds, which funds are hereby created. Such moneys MONEY shall be utilized for expenditures authorized or contemplated by and not inconsistent with the provisions of this part 10 relating to newborn screening, follow-up care, and genetic counseling and education programs and functions. All moneys MONEY credited to the newborn screening and genetic counseling cash funds shall be used as provided in this part 10 and shall not be deposited in or transferred to the general fund of this state or any other fund.

SCREENING CASH FUND FOR THE PURPOSE OF COVERING THE ONGOING DIRECT AND INDIRECT COSTS ASSOCIATED WITH THE ADMINISTRATION OF THE NEWBORN HEARING SCREENING PROGRAM. ALL MONEY COLLECTED PURSUANT TO SECTION 25-4-1004.7 SHALL BE TRANSMITTED TO THE STATE TREASURER, WHO SHALL CREDIT IT TO THE NEWBORN HEARING SCREENING CASH FUND. THE MONEY IN THE CASH FUND AT THE END OF ANY FISCAL YEAR SHALL REMAIN IN THE CASH FUND AND SHALL NOT BE CREDITED OR TRANSFERRED TO THE GENERAL FUND OR ANY OTHER FUND. IN ADDITION, THE GENERAL ASSEMBLY MAY APPROPRIATE MONEY FROM THE GENERAL FUND TO THE DEPARTMENT TO IMPLEMENT THE NEWBORN HEARING

-17- 1006

1	SCREENING PROGRAM THROUGH JULY 1, 2021.
2	(4) Money in the Newborn screening and genetic
3	COUNSELING CASH FUNDS AND THE NEWBORN HEARING SCREENING CASH
4	FUND ARE EXEMPT FROM SECTION 24-75-402.
5	SECTION 8. In Colorado Revised Statutes, add 25-4-1002.5 as
6	follows:
7	<b>25-4-1002.5. Definitions.</b> AS USED IN THIS PART 10, UNLESS THE
8	CONTEXT OTHERWISE REQUIRES:
9	(1) "BIRTHING FACILITY" MEANS A GENERAL HOSPITAL OR
10	BIRTHING CENTER LICENSED OR CERTIFIED PURSUANT TO SECTION
11	25-1.5-103.
12	(2) "DEPARTMENT" MEANS THE DEPARTMENT OF PUBLIC HEALTH
13	AND ENVIRONMENT.
14	(3) "STATE BOARD" MEANS THE STATE BOARD OF HEALTH IN THE
15	DEPARTMENT.
16	SECTION 9. In Colorado Revised Statutes, 24-75-302, amend
17	<b>as added by House Bill 18-1173</b> (2.3)(c) and (2.3)(d); and <b>add</b> (2.3)(e)
18	as follows:
19	24-75-302. Capital construction fund - capital assessment fees
20	- calculation - information technology capital account. (2.3) In
21	addition to the sums transferred pursuant to subsections (2) and (2.5) of
22	this section, the state treasurer and the controller shall transfer a sum as
23	specified in this subsection (2.3) from the general fund to the information
24	technology capital account created in subsection (3.7) of this section, as
25	enacted by House Bill 15-1266, as money becomes available in the
26	general fund during the fiscal year beginning on July 1 of the fiscal year
27	in which the transfer is made. Transfers between funds pursuant to this

-18-

1	subsection (2.3) are not appropriations subject to the limitations of section
2	24-75-201.1. The amounts transferred pursuant to this subsection (2.3) are
3	as follows:
4	(c) On July 1, 2017, nineteen million eight hundred fifty-five
5	thousand five hundred fifteen dollars; and
6	(d) On April 1, 2018, two million eight hundred eighty-eight
7	thousand five hundred twenty-nine dollars; AND
8	(e) On July 1, 2018, seven hundred thousand dollars.
9	<b>SECTION 10.</b> Capital construction appropriation. (1) For the
10	2018-19 state fiscal year, \$700,000 is appropriated to the department of
11	public health and environment for use by the center for health and
12	environmental information. This appropriation is from the information
13	technology capital account within the capital construction fund created in
14	section 24-75-302 (3.7), C.R.S. To implement this act, the center may use
15	this appropriation for capital construction related to an information
16	technology system for hearing loss screening. Any money appropriated
17	in this subsection (1) not expended prior to July 1, 2019, is further
18	appropriated to the division for the 2019-20 and 2020-21 state fiscal years
19	for the same purpose.
20	(2) For the 2018-19 state fiscal year, \$642,500 is appropriated to
21	the department of public health and environment for use by the laboratory
22	services division. This appropriation is from the newborn screening and
23	genetic counseling cash funds created in section 25-4-1006 (1), C.R.S. To
24	implement this act, the division may use this appropriation for capital
25	construction related to laboratory space expansion. Any money
26	appropriated in this subsection (2) not expended prior to July 1, 2019, is
27	further appropriated to the division for the 2019-20 and 2020-21 state

-19- 1006

1	fiscal years for the same purpose.
2	<b>SECTION 11. Appropriation.</b> (1) For the 2018-19 state fiscal
3	year, \$89,222 is appropriated to the department of public health and
4	environment for use by the center for health and environmental
5	information. This appropriation is from the newborn hearing screening
6	cash fund created in section 25-4-1006 (3), C.R.S., and is based on the
7	assumption that the center will require an additional 1.0 FTE. To
8	implement this act, the center may use this appropriation the birth defects
9	monitoring and prevention program.
10	(2) For the 2018-19 state fiscal year, \$520,000 is appropriated to
11	the department of public health and environment for use by the laboratory
12	services division. This appropriation is from the newborn screening and
13	genetic counseling cash funds created in section 25-4-1006 (1), C.R.S. To
14	implement this act, the division may use this appropriation for chemistry
15	and microbiology operating expenses.
16	<b>SECTION 12.</b> Effective date. This act takes effect July 1, 2018.
17	<b>SECTION 13.</b> Safety clause. The general assembly hereby finds,
18	determines, and declares that this act is necessary for the immediate

preservation of the public peace, health, and safety.

19

-20- 1006