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HOUSE BILL 18-1006

BY REPRESENTATIVE(S) Hamner and Liston, Arndt, Becker K., Bridges, Buckner, Danielson, Esgar, Exum, Garnett, Gray, Hansen, Jackson, Kennedy, Lee, McLachlan, Michaelson Jenet, Pabon, Pettersen, Roberts, Rosenthal, Winter, Young, Duran, Coleman, Ginal, Hooton, Kraft-Tharp, Melton, Salazar, Valdez;
also SENATOR(S) Gardner and Moreno, Aguilar, Court, Crowder, Fields, Jahn, Jones, Kefalas, Kerr, Lambert, Lundberg, Martinez Humenik, Merrifield, Priola, Tate, Todd, Zenzinger.

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

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

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

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

25-4-1002. Legislative declaration. (1) The general assembly

Capital letters or bold & italic numbers indicate new material added to existing statutes; dashes through words indicate deletions from existing statutes and such material not part of act.

hereby finds and declares that:

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

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

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

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

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

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

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

(h) Participation of persons in NEWBORN SCREENING PROGRAMS OR genetic counseling programs in this state should be wholly voluntary, and that all information obtained from persons involved in such THESE programs ~~or in newborn screening programs~~ in the state ~~should~~ MUST be

held strictly confidential. FAMILY PARTICIPATION IN THE FOLLOW-UP SUPPORT AND ASSISTANCE SERVICES IS VOLUNTARY.

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

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

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

(l) CHILDREN WITH HEARING LOSS WHO DO NOT RECEIVE EARLY INTERVENTION AND TREATMENT FREQUENTLY REQUIRE SPECIAL EDUCATIONAL SERVICES, WHICH, FOR THE VAST MAJORITY OF CHILDREN IN THE STATE WITH HEARING NEEDS, ARE PUBLICLY FUNDED; AND

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

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

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

(e) All information gathered by the department of ~~public health and environment~~, or by other agencies, entities, and individuals conducting programs and projects on newborn screening and genetic counseling and

education, other than statistical information and information ~~which~~ THAT the ~~individual~~ PARENT OR GUARDIAN OF A NEWBORN allows to be released through ~~his~~ THE PARENT'S OR GUARDIAN'S informed consent, ~~shall be~~ IS confidential. Public and private access to ~~individual~~ NEWBORN patient data ~~shall be~~ IS limited to data compiled without the ~~individual's~~ NEWBORN'S name. THE INFORMATION GATHERED PURSUANT TO THIS SUBSECTION (2)(e) DOES NOT RESTRICT THE DEPARTMENT FROM PERFORMING FOLLOW-UP SERVICES WITH NEWBORNS, THEIR PARENTS OR GUARDIANS, AND HEALTH CARE PROVIDERS.

SECTION 4. In Colorado Revised Statutes, 25-4-1004, **amend** (1)(b), (1)(c) introductory portion, and (2); and **add** (1.5) and (3) as follows:

25-4-1004. Newborn screening - advisory committee - rules.

(1) (b) ~~On or after April 1, 1989, all~~ Infants born in the state of Colorado shall be tested for the following conditions: Phenylketonuria, hypothyroidism, abnormal hemoglobins, galactosemia, cystic fibrosis, biotinidase deficiency, and such other conditions as the STATE board of health may determine meet the criteria set forth in ~~paragraph (c) of this subsection (1).~~ Appropriate specimens for such testing shall be forwarded by the hospital in which the child is born to the laboratory operated or designated by the department of public health and environment for such purposes SUBSECTION (1)(c) OF THIS SECTION. THE BIRTHING FACILITY WHERE THE INFANT IS BORN SHALL FORWARD ALL APPROPRIATE SPECIMENS TO THE LABORATORY OPERATED OR DESIGNATED BY THE DEPARTMENT. The physician, nurse, midwife, or other health professional attending a birth outside a ~~hospital shall be~~ BIRTHING FACILITY IS responsible for the ~~collection~~ COLLECTING and forwarding of ~~such~~ THE specimens. The LABORATORY SHALL FORWARD THE results of the testing ~~shall be forwarded~~ directly to the physician, PRIMARY CARE PROVIDER, or other ~~primary~~ health care provider AS NEEDED for the provision of such information to the parent, ~~or~~ parents, OR GUARDIANS of the child. The results of any testing or follow-up testing pursuant to section 25-4-1004.5 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 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. TESTING UNDER THIS SUBSECTION (1)(b) IS NOT

REQUIRED IF THE PARENT OR LEGAL GUARDIAN OBJECTS.

(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):

(1.5) IF THE DEPARTMENT DEEMS THAT NEW CONDITIONS FOR WHICH AN INFANT MUST BE TESTED SHOULD BE ADDED, THE DEPARTMENT SHALL REPORT THE ADDED CONDITIONS TO THE GENERAL ASSEMBLY DURING ITS PRESENTATION IN ACCORDANCE WITH THE "STATE MEASUREMENT FOR ACCOUNTABLE, RESPONSIVE, AND TRANSPARENT (SMART) GOVERNMENT ACT", PART 2 OF ARTICLE 7 OF TITLE 2. THE DEPARTMENT SHALL ALSO NOTIFY THE JOINT BUDGET COMMITTEE AND THE HEALTH AND HUMAN SERVICES COMMITTEE OF THE SENATE AND THE HEALTH, INSURANCE, AND ENVIRONMENT COMMITTEE AND THE PUBLIC HEALTH CARE AND HUMAN SERVICES COMMITTEE OF THE HOUSE OF REPRESENTATIVES, OR THEIR SUCCESSOR COMMITTEES, WITHIN SIXTY DAYS AFTER THE DEPARTMENT RECOMMENDS A NEW CONDITION AND INCLUDE THE ADDED CONDITIONS IN THE DEPARTMENT'S ANNUAL BUDGET REQUEST SUBMITTED TO THE GENERAL ASSEMBLY EACH NOVEMBER 1.

(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:

(I) IN ADDITION TO THOSE CONDITIONS LISTED IN SUBSECTION (1)(b) OF THIS SECTION, ANY OTHER CONDITIONS FOR WHICH TESTING MUST OCCUR;

(II) OBTAINING SAMPLES OR SPECIMENS FROM NEWBORN INFANTS

REQUIRED FOR THE TESTS PRESCRIBED BY THE STATE BOARD; AND

(III) THE HANDLING AND DELIVERY OF SAMPLES OR SPECIMENS FOR TESTING AND EXAMINATION.

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

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

~~(a) Newborn screening authorized by section 25-4-1004 is provided for every newborn in the state;~~

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

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

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

~~(e) A nominal increase of the fee on newborn screening to cover 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.~~

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

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

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

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

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

(c) On and after July 1, ~~1996~~ 2018, the executive director of the department of public health and environment may adjust the newborn screening fee set forth in section 25-4-1004 (2) so that the fee is sufficient to cover the costs associated with the second screening described in this subsection (3). ~~Any increase shall be in addition to the fee described in subsection (2) of this section and shall not initially exceed five dollars and seventy-five cents but may be adjusted annually to reflect any actual cost increase associated with the administration of the second screening. Any fees collected pursuant to this paragraph (c) shall be subject to the provisions of section 25-4-1006~~ MONEY IN THE NEWBORN SCREENING AND GENETIC COUNSELING CASH FUNDS IS EXEMPT FROM SECTION 24-75-402 THROUGH JULY 1, 2021.

SECTION 6. In Colorado Revised Statutes, 25-4-1004.7, **amend** (2)(a)(I) introductory portion, (2)(a)(I)(A), (2)(a)(I)(C), (2)(a)(II), (3)(a), and (5); **repeal** (1), (2)(a)(I)(B), (3)(b), and (4)(a); and **add** (7), (8), (9), (10), and (11) as follows:

25-4-1004.7. Newborn hearing screening - advisory committee - report - rules. (1) ~~(a) The general assembly finds, determines, and declares:~~

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

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

~~(HH) That early detection of hearing loss in a child and early~~

~~intervention and treatment has been demonstrated to be highly effective in facilitating a child's healthy development in a manner consistent with 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 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 section. Toward that end, every licensed or certified ~~hospital~~ BIRTHING FACILITY shall educate the parents of infants born in such ~~hospitals~~ BIRTHING FACILITIES of the importance of screening the hearing of newborn infants and follow-up care. Education ~~shall not be~~ IS NOT considered a substitute for the hearing screening described in this section. ~~Every licensed or certified hospital shall report annually to the advisory committee concerning the following:~~ SCREENING FOR HEARING LOSS UNDER THIS SUBSECTION (3)(a) IS NOT REQUIRED IF THE PARENT OR LEGAL GUARDIAN OBJECTS.

~~(I) The number of infants born in the hospital;~~

~~(H) The number of infants screened;~~

~~(HH) The number of infants who passed the screening, if administered; and~~

~~(IV) The number of infants who did not pass the screening, if administered.~~

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

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

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

(5) A physician, nurse, midwife, or other health professional attending a birth outside a hospital or institution shall MAKE EVERY PROFESSIONAL EFFORT, AS DEFINED BY THE BOARD, INCLUDING FOLLOWING UP AT SCHEDULED POSTPARTUM APPOINTMENTS, TO ENSURE THAT THE HEARING SCREENING IS PERFORMED WITHIN THIRTY DAYS OF THE BIRTH AND SHALL provide information, as established by RULE OF the department, to parents regarding ~~places where the parents may have their infants' hearing screened~~ and the importance of ~~such~~ THE screening. THE PHYSICIAN, NURSE, MIDWIFE, OR OTHER HEALTH PROFESSIONAL WHO PERFORMS THE SCREENING SHALL PROVIDE A REPORT OF ANY SCREENING TO THE PARENT OR GUARDIAN OF THE INFANT, THE PRIMARY CARE PROVIDER OF THE INFANT, AND THE DEPARTMENT. SCREENING FOR HEARING LOSS UNDER THIS SUBSECTION (5) IS NOT REQUIRED IF THE PARENT OR LEGAL GUARDIAN OBJECTS.

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

(8) (a) THE STATE BOARD OF HEALTH SHALL PROMULGATE RULES THAT REQUIRE EACH OF THE FOLLOWING WITH INFORMATION PERTINENT TO THIS SECTION TO REPORT THE RESULTS OF INDIVIDUAL SCREENING TO THE DEPARTMENT:

(I) A BIRTHING FACILITY; OR

(II) ANOTHER FACILITY OR PROVIDER.

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

(9)(a) THE STATE BOARD OF HEALTH SHALL PROMULGATE RULES TO ESTABLISH AND MAINTAIN APPROPRIATE FOLLOW-UP SERVICES FOR NEWBORNS AT RISK OF HEARING LOSS. THE FOLLOW-UP SERVICES MUST INCLUDE IDENTIFICATION OF NEWBORNS AT RISK FOR HEARING LOSS, COORDINATION AMONG MEDICAL AND AUDIOLOGY PROVIDERS AND FAMILIES, CONNECTING NEWBORNS TO TIMELY INTERVENTION, APPROPRIATE REFERRALS TO SPECIALISTS FOR FOLLOW-UP AND DIAGNOSTIC TESTING, AND ADDITIONAL DUTIES AS DETERMINED BY THE DEPARTMENT.

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

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

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

NEWBORNS, THEIR PARENTS OR GUARDIANS, AND HEALTH CARE PROVIDERS.

(10)(a) THE DEPARTMENT SHALL DEVELOP AND PUBLISH MATERIALS ON ITS WEBSITE FOR USE IN EDUCATING AND TRAINING ON CYTOMEGALOVIRUS, REFERRED TO AS "CMV", THAT INCLUDE THE FOLLOWING:

(I) THE ESTIMATED INCIDENCE OF CMV;

(II) THE TRANSMISSION OF CMV TO PREGNANT WOMEN OR WOMEN WHO MAY BECOME PREGNANT;

(III) BIRTH DEFECTS CAUSED BY CONGENITAL CMV;

(IV) METHODS OF DIAGNOSING CONGENITAL CMV;

(V) AVAILABLE PREVENTIVE MEASURES TO AVOID THE INFECTION IN WOMEN WHO ARE PREGNANT OR MAY BECOME PREGNANT;

(VI) RESOURCES AND EVIDENCE-BASED TREATMENT AS THEY BECOME AVAILABLE FOR FAMILIES OF CHILDREN BORN WITH CMV; AND

(VII) ANY FEDERAL OR STATE REQUIREMENTS REGARDING TESTING FOR CMV.

(b) SUBJECT TO AVAILABLE APPROPRIATIONS, THE DEPARTMENT SHALL PROVIDE TECHNICAL ASSISTANCE AND TRAINING REGARDING CMV TO HEALTH CARE FACILITIES AND HEALTH CARE PROVIDERS UPON REQUEST.

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

SECTION 7. In Colorado Revised Statutes, **amend** 25-4-1005 as

follows:

25-4-1005. Exceptions. Nothing in the provisions of this part 10 shall be construed to require the testing or medical treatment for the minor child of any person WHO HAS PERSONAL OBJECTION TO THE ADMINISTRATION OF THE TESTS OR TREATMENT or of any person who is a member of a well-recognized church or religious denomination and whose religious convictions in accordance with the tenets or principles of his THE church or religious denomination are against medical treatment for disease or physical defects. ~~or has a personal objection to the administration of such tests or treatment.~~

SECTION 8. 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.

(3) THERE IS HEREBY CREATED THE NEWBORN HEARING 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 SCREENING PROGRAM.

(4) MONEY IN THE NEWBORN SCREENING AND GENETIC COUNSELING CASH FUNDS AND THE NEWBORN HEARING SCREENING CASH FUND ARE EXEMPT FROM SECTION 24-75-402 THROUGH JULY 1, 2021.

SECTION 9. In Colorado Revised Statutes, **add** 25-4-1002.5 as follows:

25-4-1002.5. Definitions. AS USED IN THIS PART 10, UNLESS THE CONTEXT OTHERWISE REQUIRES:

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

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

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

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

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

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

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

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

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

(2) For the 2018-19 state fiscal year, \$1,162,500 is appropriated to the department of public health and environment for use by the laboratory services division. This appropriation is from the newborn screening and genetic counseling cash funds created in section 25-4-1006 (1), C.R.S. To implement this act, the division may use this appropriation for capital construction related to laboratory space expansion and equipment purchase. Any money appropriated in this subsection (2) not expended prior to July 1, 2019, is further appropriated to the division for the 2019-20 and 2020-21 state fiscal years for the same purpose.

SECTION 12. Appropriation. For the 2018-19 state fiscal year, \$89,222 is appropriated to the department of public health and environment for use by the center for health and environmental information. This appropriation is from the newborn hearing screening cash fund created in section 25-4-1006 (3), C.R.S., and is based on the assumption that the center will require an additional 1.0 FTE. To implement this act, the center may use this appropriation for the birth defects monitoring and prevention program.

SECTION 13. Effective date. This act takes effect July 1, 2018.

SECTION 14. Safety clause. The general assembly hereby finds,

determines, and declares that this act is necessary for the immediate preservation of the public peace, health, and safety.

Crisanta Duran
SPEAKER OF THE HOUSE
OF REPRESENTATIVES

Kevin J. Grantham
PRESIDENT OF
THE SENATE

Marilyn Eddins
CHIEF CLERK OF THE HOUSE
OF REPRESENTATIVES

Effie Ameen
SECRETARY OF
THE SENATE

APPROVED _____

John W. Hickenlooper
GOVERNOR OF THE STATE OF COLORADO