

CHAPTER 222

HEALTH AND ENVIRONMENT**HOUSE BILL 96-1030**

BY REPRESENTATIVES Tucker, Clarke, Kerns, Knox, Lyle, Mace, Nichol, Prinster, Snyder, Sullivan, and Swenson;
also SENATORS Wham, Bishop, Hernandez, Hopper, Johnson, Linkhart, Martinez, Pascoe, L. Powers, Rupert, Schroeder, Tanner,
and Weddig.

AN ACT**CONCERNING SCREENING PROCEDURES FOR GENETIC HEALTH CONDITIONS IN NEWBORN INFANTS,
AND MAKING AN APPROPRIATION IN CONNECTION THEREWITH.**

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

SECTION 1. 25-4-1004 (1) (b), Colorado Revised Statutes, 1989 Repl. Vol., as amended, is amended to read:

25-4-1004. Newborn screening. (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, ~~homocystinuria, maple syrup urine disease,~~ cystic fibrosis, biotinidase deficiency, and such other conditions as the 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. The physician, nurse, midwife, or other health professional attending a birth outside a hospital shall be responsible for the collection and forwarding of such specimens. The results of the testing shall be forwarded directly to the physician or other primary health care provider for the provision of such information to the parent or parents of the child. The STATE board of health may discontinue testing for any condition listed in this paragraph (b) if, upon consideration of criteria set forth in paragraph (c) of this subsection (1), the board finds that the public health is better served by not testing infants for that condition. The ~~health~~ department OF PUBLIC HEALTH AND ENVIRONMENT shall submit a report to the house and senate health, environment, welfare, and institutions committees on or before January 15, 1993, concerning the newborn screening program. Such report shall include the history of the newborn

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

screening program and criteria used for the addition or deletion of tests utilized under this section.

SECTION 2. 25-4-1004.5 (1), Colorado Revised Statutes, 1989 Repl. Vol., as amended, is amended BY THE ADDITION OF A NEW PARAGRAPH to read:

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

(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.

SECTION 3. 25-4-1004.5, Colorado Revised Statutes, 1989 Repl. Vol., as amended, is amended BY THE ADDITION OF THE FOLLOWING NEW SUBSECTIONS to read:

25-4-1004.5. Follow-up testing and treatment - second screening - legislative declaration - fee - rules. (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 HAVE A SECOND SPECIMEN TAKEN TO SCREEN FOR THE FOLLOWING CONDITIONS:

(I) PHENYLKETONURIA;

(II) HYPOTHYROIDISM;

(III) GALACTOSEMIA;

(IV) CYSTIC FIBROSIS; AND

(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 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:

(I) IDENTIFICATION OF THOSE CONDITIONS FOR WHICH A SECOND SPECIMEN SHALL

BE REQUIRED;

(II) THE AGE OF THE INFANT AT WHICH THE SECOND SCREENING MAY BE ADMINISTERED;

(III) THE METHOD BY WHICH THE PARENT OR PARENTS OF A NEWBORN SHALL BE ADVISED OF THE NECESSITY FOR A SECOND SPECIMEN TEST;

(IV) THE PROCEDURE TO BE FOLLOWED IN ADMINISTERING THE SECOND SPECIMEN TEST;

(V) ANY EXCEPTIONS TO THE NECESSITY FOR A SECOND SPECIMEN TEST AND THE PROCEDURES TO BE FOLLOWED IN SUCH CASES; AND

(VI) THE STANDARDS OF SUPERVISION AND QUALITY CONTROL THAT SHALL APPLY TO SECOND SPECIMEN TESTING.

(c) ON AND AFTER JULY 1, 1996, 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.

(4) THE PROVISIONS OF SECTION 25-4-1003 (2) SHALL APPLY TO SECOND NEWBORN SCREENINGS.

SECTION 4. Appropriation. In addition to any other appropriation, there is hereby appropriated, out of any moneys in the newborn screening and genetic counseling cash fund not otherwise appropriated, to the department of public health and environment, for the fiscal year beginning July 1, 1996, the sum of one hundred four thousand four hundred ten dollars (\$104,410), or so much thereof as may be necessary, for the implementation of this act.

SECTION 5. Effective date. This act shall take effect July 1, 1996.

SECTION 6. 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.

Approved: May 30, 1996