# House Bill 2563

Sponsored by Representatives MCLAIN, SOLLMAN, SCHOUTEN; Representatives NOSSE, SALINAS (Presession filed.)

**SUMMARY**

The following summary is not prepared by the sponsors of the measure and is not a part of the body thereof subject to consideration by the Legislative Assembly. It is an editor's brief statement of the essential features of the measure **as introduced.**

Directs Oregon Health Authority to adopt rules requiring infants to be screened to detect certain diseases.

Takes effect on 91st day following adjournment sine die.

**A BILL FOR AN ACT**

Relating to screening newborns for diseases; creating new provisions; amending ORS 418.325 and 433.285; and prescribing an effective date.

**Be It Enacted by the People of the State of Oregon:**

**SECTION 1. (1) The Oregon Health Authority shall adopt rules requiring that every infant delivered in this state be given tests approved by the authority for the detection of the following diseases:**

**(a) Propionic acidemia (PA).**

**(b) Methylmalonic acidemia (MMA).**

**(c) Isovaleric acidemia (IVA).**

**(d) 3-methylcrotonyl-CoA carboxylase deficiency (3-MCCD).**

**(e) 3-hydroxy-3-methylglutaryl- CoA lyase deficiency (HMG-CoA-LD).**

**(f) Multiple carboxylase deficiency (MCD).**

**(g) Beta-ketothiolase deficiency (BKT).**

**(h) Glutaric acidemia type I (GA-1).**

**(i) Malonic acidemia (MAL).**

**(j) Isobutyryl-CoA dehydrogenase deficiency (IBDD).**

**(k) 2-methylbutyryl-CoA dehydrogenase deficiency (2-MBCDD).**

**(L) 3-methylglutaconyl-CoA hydratase deficiency (3MGH).**

**(m) 2-methyl-3-hydroxybutyryl-CoA dehydrogenase deficiency (MHBDD).**

**(n) Carnitine uptake defect (CUD).**

**(o) Medium-chain acyl-CoA dehydrogenase deficiency (MCADD).**

**(p) Very long-chain acyl-CoA dehydrogenase deficiency (VLCADD).**

**(q) Long-chain 3-hydroxyacyl-CoA dehydrogenase deficiency (LCHADD).**

**(r) Trifunctional protein deficiency (TFPD).**

**(s) Short-chain acyl-CoA dehydrogenase deficiency (SCADD).**

**(t) Glutaric acidemia type II (GA2).**

**(u) Carnitine palmitoyltransferase types I and II (CPT I and CPT II) deficiency.**

**(v) Carnitine-acylcarnitine translocase deficiency (CACTD).**

**(w) Argininosuccinate lyase deficiency (ASLD).**

**NOTE:** Matter in **boldfaced** type in an amended section is new; matter [*italic and bracketed*] is existing law to be omitted. New sections are in **boldfaced** type.

**(x) Citrullinemia type I (CTLN1).**

**(y) Maple syrup urine disease (MSUD).**

**(z) Homocystinuria (HCY).**

**(aa) Phenylketonuria (PKU).**

**(bb) Tyrosinemia types I, II, and III.**

**(cc) Arginase deficiency (ARGD).**

**(dd) Primary congenital hypothyroidism (CH).**

**(ee) Congenital adrenal hyperplasia (CAH).**

**(ff) Cystic fibrosis.**

**(gg) Biotinidase deficiency.**

**(hh) Classic galactosemia.**

**(ii) Sickle cell anemia.**

**(jj) Severe combined immunodeficiency (SCID).**

**(kk) Pompe (glycogen storage disease type II).**

**(LL) Mucopolysaccharidosis type I (MPS I).**

**(mm) Fabry disease (alpha-galactosidase A deficiency).**

**(nn) Gaucher disease (glucocerebrosidase deficiency).**

**(oo) Biopterin defect in cofactor biosynthesis (BIOPT-BS).**

**(pp) Biopterin defect in cofactor regeneration (BIOPT-REG).**

**(qq) Carbamoyl Phosphate Synthetase I Deficiency (CPSID).**

**(rr) Hyperornithine with gyrate deficiency (Hyper ORN).**

**(ss) Nonketotic hyperglycinemia (NKH).**

**(tt) Ornithine transcarbamylase deficiency (OTCD).**

**(uu) 2,4 Dienoyl-CoA reductase deficiency (DECRED).**

**(vv) Hemoglobinopathies (Var Hb).**

**(ww) S, beta-thalassemia (Hb S/ßTh).**

**(xx) Krabbe disease.**

**(yy) Adrenoleukodystrophy (ALD).**

**(zz) Critical congenital heart disease (CCHD).**

**(aaa) Hyperornithinemia-hyperammonemia-homocitrullinuria (HHH) syndrome.**

**(bbb) Other diseases specified by the authority by rule.**

**(2) The authority by rule shall specify the appropriate time following delivery for collecting specimens, the manner in which the specimens are to be submitted, the persons responsible for submitting the specimens, the methods of testing and the manner of payment of fees for testing.**

**(3) The testing required by subsection (1) of this section may not be required if the infant is being reared as an adherent to a religion the teachings of which are opposed to such testing. The person responsible for submitting specimens under the rules of the authority is responsible for submitting a statement signed by the infant's parent that the infant is being so reared. The authority by rule shall prescribe the form of the statement.**

**(4) The authority shall adopt by rule a procedure for waiving the fees established under subsection (2) of this section so that no infant is refused testing because of the parent's inability to pay the fee.**

**(5) The authority by rule shall prescribe the procedure to be followed in cases where initial testing for a disease is administered too early to detect the disease, where the sample**

**submitted for testing is improperly collected and where a sample shows an abnormal result. The authority, within the limits of funds available from fees collected under this section, shall institute a pilot program for follow-up on abnormal test results.**

**SECTION 2.** ORS 433.285 is amended to read:

433.285. [*(1)*] It hereby is declared to be a matter of public policy of the State of Oregon that in the interest of public health and the prevention of mental retardation, every infant, shall be given tests approved by the Oregon Health Authority for the detection of the disease of phenylketonuria and other metabolic diseases.

[*(2) The authority by rule shall specify the diseases for which infants shall be tested under subsection (1) of this section, the appropriate time following delivery for collecting specimens, the manner in which the specimens are to be submitted, the persons responsible for submitting the specimens, the methods of testing and the manner of payment of the fees.*]

[*(3) The testing required by subsection (1) of this section shall not be required if the infant is being reared as an adherent to a religion the teachings of which are opposed to such testing. The person responsible for submitting specimens under the rules of the authority shall be responsible for submitting a statement signed by the infant's parent that the infant is being so reared. The authority by rule shall prescribe the form of the statement.*]

[*(4) The authority shall adopt by rule a procedure whereby the fees established under subsection (2) of this section shall be waived and no infant refused service because of the parent's inability to pay the fee.*]

[*(5) The authority by rule shall prescribe the procedure to be followed in cases where initial testing for metabolic diseases is administered too early to detect these diseases, where the sample submitted for testing is improperly collected and where a sample shows an abnormal result. The authority, within the limits of funds available from fees collected under this section, shall institute a pilot program for follow-up on abnormal test results.*]

**SECTION 3.** ORS 418.325 is amended to read:

418.325. (1) A child-caring agency that is subject to ORS 418.205 to 418.327, 418.470, 418.475 or 418.950 to 418.970 shall safeguard the health of each child, ward or other dependent or delinquent child to whom the agency provides care or services by providing for medical examinations of each child by a qualified physician or naturopathic physician at the following intervals:

(a) Three examinations during the first year of the child's life;

(b) One examination during the second year of the child's life;

(c) One examination at the age of four;

(d) One examination at the age of six;

(e) One examination at the age of nine; and

(f) One examination at the age of 14.

(2) If an examination under subsection (1) of this section has not occurred within six months prior to the transfer for adoption of the custody of a child by a child-caring agency to the prospective adoptive parents of such child, a child-caring agency shall provide for a medical examination of such child within six months prior to such transfer.

(3) Any testing that occurs at intervals other than those specified in subsections (1) and (2) of this section shall not be considered to be in lieu of the required examinations. However, nothing in subsections (1) and (2) of this section is intended to limit more frequent examinations that are dictated by the general state of the child's health or by any particular condition.

(4) Within 90 days of obtaining custody of a child under six years of age, a child-caring agency

shall provide for the child to be:

(a) Inoculated as determined appropriate by the local health department; and

(b) Tested for:

(A) Phenylketonuria pursuant to [*ORS 433.285*] **section 1 of this 2019 Act**;

(B) Visual and aural acuity consistent with the child's age;

(C) Sickle-cell anemia;

(D) Effects of rubella, if any;

(E) Effects of parental venereal disease, if any; and

(F) The hereditary or congenital effects of parental use of drugs or controlled substances.

(5) Within six months prior to the transfer for adoption of the custody of a child by a child-caring agency to the prospective adoptive parents of such child, the child-caring agency shall provide for such child to have a complete physical examination by a physician or naturopathic physician, including but not limited to inspection for evidence of child abuse in accordance with rules of the Department of Human Services, and be tested for visual and aural acuity consistent with the child's age.

(6) A child-caring agency shall record the results of tests provided a child pursuant to subsections (1) to (5) of this section in the child's health record. The child's health record shall be kept as a part of the agency's total records of that child. The child's health record shall be made available to both natural parents and to both prospective foster or adoptive parents of that child. A qualified member of a child-caring agency under the supervision of a qualified physician or naturopathic physician shall explain to adoptive parents the medical factors possible as a result of a child's birth history, hereditary or congenital defects, or disease or disability experience.

**SECTION 4. This 2019 Act takes effect on the 91st day after the date on which the 2019 regular session of the Eightieth Legislative Assembly adjourns sine die.**