

## **Ohio Legislative Service Commission**

### **Bill Analysis**

Amy J. Rinehart

# H.B. 183\* 130th General Assembly (As Introduced)

Rep. Barnes

#### **BILL SUMMARY**

- Codifies the 35 genetic, endocrine, and metabolic disorders that newborn children currently must be screened for under the Newborn Screening Program.
- Requires that rules the Director of Health must adopt governing the Program include standards and procedures for giving information to a child's parents regarding each disorder for which the screening or rescreening result was abnormal.
- Declares an emergency.

#### **CONTENT AND OPERATION**

#### **Newborn Screening Program**

The bill codifies the list of 35 genetic, endocrine, and metabolic disorders that newborn children must currently be screened for under the Newborn Screening Program.<sup>1</sup> Currently, the list of disorders is specified by the Director of Health in an administrative rule.<sup>2</sup>

The bill eliminates an existing provision requiring the Director of Health to adopt rules specifying the disorders to be included in each newborn screening.<sup>3</sup> It makes conforming changes to eliminate the provision requiring the Newborn Screening

<sup>\*</sup> This analysis was prepared before the report of the bill's introduction appeared in the House Journal. Note that the list of co-sponsors may be incomplete.

<sup>&</sup>lt;sup>1</sup> Revised Code (R.C.) 3701.501(C).

<sup>&</sup>lt;sup>2</sup> Ohio Administrative Code 3701-55-02(A).

<sup>&</sup>lt;sup>3</sup> R.C. 3701.501(C)(1).

Advisory Council to evaluate genetic, endocrine, and metabolic disorders to assist the Director regarding which disorders should be included in the screenings but maintains the Council's purpose to advise the Director regarding newborn screening.<sup>4</sup>

The bill requires each hospital and freestanding birthing center to screen a newborn born in the hospital or center for all of the following genetic, endocrine, or metabolic disorders (the same disorders currently specified by rule):<sup>5</sup>

(1) Argininemia; (2) Argininosuccinic acidemia; (3) Biotinidase deficiency; (4) Carnitine/acylcarnitine translocase deficiency; (5) Carnitine palmitoyl transferase deficiency type II; (6) Carnitine uptake defect; (7) Citrullinemia; (8) Congenital adrenal hyperplasia; (9) Congenital hypothyroidism; (10) Cystic fibrosis; (11) Galactosemia; (12) Glutaric acidemia type I; (13) Glutaric acidemia type II; (14) Homocystinuria (cystathionine-beta-synthase deficiency); (15) Hypermethioninemia; (16) Isobutyryl-CoA dehydrogenase deficiency; (17) Isovaleric acidemia;

-2-

<sup>&</sup>lt;sup>4</sup> R.C. 3701.501(C)(2).

<sup>&</sup>lt;sup>5</sup> R.C. 3701.501(C).

- (18) Long chain hydroxyacyl-CoA dehydrogenase deficiency;
- (19) Maple syrup urine disease;
- (20) Medium chainacyl-CoA dehydrogenase deficiency;
- (21) Methylmalonic acidemia;
- (22) Multiple CoA carboxylase deficiency;
- (23) Phenylketonuria;
- (24) Propionic acidemia;
- (25) Short chain acyl-CoA dehydrogenase deficiency;
- (26) Trifunctional protein deficiency;
- (27) Tyrosinemia type-I;
- (28) Tyrosinemia type-II;
- (29) Tyrosinemia type-III;
- (30) Very long chain acyl-CoA dehydrogenase deficiency;
- (31) 2-methylbutyryl-CoA dehydrogenase deficiency;
- (32) 3-hydroxy-3-methylglutaryl-CoA lyase deficiency;
- (33) 3-ketothiolase deficiency;
- (34) 3-methylcrotonyl-CoA carboxylase deficiency;
- (35) Sickle cell and other hemoglobinopathies.

#### Information provided to newborn's parents

The Director is required by existing law to adopt rules regarding communicating to a newborn's parents the results of any screenings or rescreenings performed under the Newborn Screening Program.<sup>6</sup> The bill requires, in addition, that the rules include

<sup>&</sup>lt;sup>6</sup> R.C. 3701.501(D).

standards and procedures for giving information to a child's parents regarding each disorder for which the screening or rescreening result was abnormal.<sup>7</sup>

#### **Background – Newborn Screening Program**

The purpose of the Newborn Screening Program is to identify newborn infants who may be at risk for rare but serious disorders. If left untreated, these disorders can lead to slow growth, blindness, mental retardation, and possibly death. Detecting these problems early and providing appropriate treatment may prevent serious complications from developing later.<sup>8</sup> Screening is required unless the child's parents object to the screening on religious grounds.<sup>9</sup>

The screening must be conducted at least 24 hours after birth and before the infant is five days of age. The process for identifying the genetic, metabolic, or endocrine disorders that cause the serious health problems includes taking a few drops of blood from an infant's heel and sending the sample to the state's newborn screening laboratory for testing.<sup>10</sup>

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<sup>7</sup> R.C. 3701.501(D)(4).

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<sup>&</sup>lt;sup>8</sup> Ohio Department of Health, *Newborn Screening Program Details* (last visited June 4, 2013), available at <a href="http://www.odh.ohio.gov/odhprograms/phl/newbrn/NBSdetails.aspx">http://www.odh.ohio.gov/odhprograms/phl/newbrn/NBSdetails.aspx</a>.

<sup>&</sup>lt;sup>9</sup> R.C. 3701.503(A)(2).

<sup>&</sup>lt;sup>10</sup> Ohio Department of Health, *Newborn Screening Program Details* (last visited June 4, 2013), available at <a href="http://www.odh.ohio.gov/odhprograms/phl/newbrn/NBSdetails.aspx">http://www.odh.ohio.gov/odhprograms/phl/newbrn/NBSdetails.aspx</a>>.