Ohio Legislative Service Commission

Bill Analysis

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S.B. 14

131st General Assembly
(As Introduced)

Sens. Faber and Lehner, Widener, Uecker, Gardner, Patton, Eklund, Jones

BILL SUMMARY

- Requires Krabbe disease to be a disorder for which newborns are screened under the Newborn Screening Program.
- Specifies that the bill be known as the "Madison Layton Act."

CONTENT AND OPERATION

Newborn screening for Krabbe disease

The bill requires Krabbe disease to be a disorder for which newborns are screened under the Newborn Screening Program.[1] Under current law not modified by the bill, the list of disorders is specified by the Director of Health in an administrative rule.[2] The Newborn Screening Advisory Council, consisting of 14 members with an interest or expertise in newborn screening, assists the Director in determining which disorders should be included on the list.[3] Currently the list includes 36 genetic, endocrine, and metabolic disorders.[4] Additionally, newborns are screened for hearing impairments and critical congenital heart defects.[5]

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[1] R.C. 3701.501(C)(1).

[2] O.A.C. 3701-55-02(A).

[3] R.C. 3701.501(B).

[4] O.A.C. 3701-55-02(A).

[5] R.C. 3701.505 and 3701.5010 (not in the bill).

Krabbe disease is an inherited degenerative disorder that affects the nervous system; in the U.S., it affects about 1 in 100,000 individuals. The disease is caused by the deficiency of an enzyme called galactosylceramidase. This enzyme deficiency impairs the growth and maintenance of myelin, the protective covering around certain nerve cells that ensures the rapid transmission of nerve impulses. Symptoms of Krabbe disease usually begin before the age of one year and include irritability, muscle weakness, feeding difficulties, episodes of fever without any sign of infection, stiff posture, and slowed mental and physical development. As the disease progresses, muscles continue to weaken, affecting the infant's ability to move, chew, swallow, and breathe. Affected infants also experience vision loss and seizures.[6]

Name of act

The bill specifies that the act be known as the "Madison Layton Act."[7]

Background – Newborn Screening Program

The purpose of the Newborn Screening Program is to identify newborns 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.[8] Screening is required unless the newborn's parents object to the screening on religious grounds.[9]

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 include taking a few drops of blood from a newborn's heel and sending the sample to the state's newborn screening laboratory for testing. If the infant is not born in a hospital or freestanding birthing center, the midwife, physician, or local health department will help collect the blood sample before the infant reaches five days of age.[10]

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[6] U.S. National Library of Medicine, Genetics Home Reference, *Krabbe Disease* (last visited Feb. 26, 2015), available at <http://ghr.nlm.nih.gov/condition/krabbe-disease>.

[7] Section 3.

[8] Ohio Department of Health, *Newborn Screening Program (NBS)* (last updated July 29, 2013), available at <http://www.odh.ohio.gov/odhprograms/phl/newbrn/nbsdetails.aspx>.

[9] R.C. 3701.501(A)(2).

[10] Ohio Department of Health, *Newborn Screening Program (NBS)* (last updated July 29, 2013), available at <http://www.odh.ohio.gov/odhprograms/phl/newbrn/nbsdetails.aspx>.

HISTORY

ACTION	DATE
Introduced	02-02-15

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