OHIO LEGISLATIVE SERVICE COMMISSION

Bill Analysis

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H.B. 397

132nd General Assembly
(As Introduced)

Reps. Boggs and Butler, Antonio, Craig, Faber, Galonski, Kent, Koehler, Lepore-Hagan, Miller, Riedel

BILL SUMMARY

- Requires a newborn to be screened for spinal muscular atrophy.

CONTENT AND OPERATION

Screening for genetic, endocrine, and metabolic disorders

H.B. 397 requires the Director of Health to include spinal muscular atrophy as a disorder for which screening is required.[1] Under current law, each newborn child (other than one whose parent objects for religious reasons) must be screened for a total of 38 genetic, endocrine, and metabolic disorders.[2] Ohio law requires the Director of Health to specify these disorders in rule, after reviewing recommendations from the Newborn Screening Advisory Council about which disorders should be included in the screenings.[3] (At present, the advisory council consists of 14 members, including health care professionals, members of the public, and individuals representing entities such as hospitals, children's hospitals, regional genetic centers, regional sickle cell centers, and newborn screening coordinators.)[4]

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

[2] R.C. 3701.501(A). *See also* Ohio Administrative Code (O.A.C.) 3701-55-02(A). Current law requires that newborns also be screened for hearing impairments and critical congenital heart defects. *See* R.C. 3701.504 and 3701.5010, not in the bill.

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

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

Of the 38 genetic, metabolic, and endocrine disorders for which a newborn must be screened, just one, Krabbe disease, is specified in statute; the remaining 37 are required by rule based on Advisory Council recommendations.[5] H.B. 397 requires the Director to include spinal muscular atrophy as a disorder for which screening is required, just as existing law requires for Krabbe disease.[6]

Background

Advisory council recommendations

When making recommendations to the Director of Health about which genetic, metabolic, and endocrine disorders to include in the screening, Ohio law requires the Advisory Council to consider all of the following factors: (1) the disorder's incidence, mortality, and morbidity, (2) whether the disorder causes disability if diagnosis, treatment, and early intervention are delayed, (3) the potential for successful treatment of the disorder, (4) the expected benefits in relation to the risks and costs associated with screening for the disorder, and (5) whether a screening for the disorder can be conducted without taking an additional blood sample or specimen.[7]

Screening procedures

Following notice to the newborn's parent, legal guardian, or legal custodian,[8] a newborn screening is conducted at least 24 hours after birth and before five days of age. The screening involves taking a few drops of blood from the baby's heel.[9] The blood sample is then sent to the Department of Health's laboratory for analysis. Results are forwarded to the birth hospital and the newborn's health professional. If a baby is not born in a hospital or freestanding birthing center, the physician, certified nurse-midwife, certified nurse practitioner, clinical nurse specialist, or local health department is to collect the blood sample before the baby reaches five days of age.[10]

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

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

[7] R.C. 3701.501(C)(2).

[8] O.A.C. 3701-55-04.

[9] Ohio Department of Health, *Ohio Newborn Screening Program (NBS)*, available at https://www.odh.ohio.gov/odhprograms/phl/newbrn/nbsdetails.aspx.

[10] *See* O.A.C. 3701-55-05.

Spinal muscular atrophy

Spinal muscular atrophy is a genetic disease affecting the part of the nervous system that controls voluntary muscle movement. It involves the loss of nerve cells, or motor neurons, in the spinal cord.[11] As these cells are lost, muscles weaken, affecting an individual's ability to walk, crawl, breathe, or swallow.[12]

HISTORY

ACTION	DATE
Introduced	10-26-17

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[11] Muscular Dystrophy Association, *Facts About Spinal Muscular Atrophy*, available at https://www.mda.org/sites/default/files/publications/Facts_SMA_P-181.pdf.

[12] National Institutes of Health, U.S. National Library of Medicine, *Spinal Muscular Atrophy*, available at https://medlineplus.gov/spinalmuscularatrophy.html.