

OFFICE OF LEGISLATIVE RESEARCH
PUBLIC ACT SUMMARY



PA 19-176—HB 7282

Public Health Committee

**AN ACT CONCERNING NEWBORN SCREENING FOR SPINAL
MUSCULAR ATROPHY**

SUMMARY: Starting January 1, 2020, this act requires all health care institutions caring for newborn infants to test them for spinal muscular atrophy, unless a parent objects based on religious grounds. It requires the institutions to administer the test as soon as it is medically appropriate.

Like the cystic fibrosis and critical congenital heart disease tests existing law requires, the spinal muscular atrophy test is performed in addition to, but separate from, the state's newborn screening program for genetic and metabolic disorders. That program, in addition to screening, directs parents of identified infants to counseling and treatment.

EFFECTIVE DATE: October 1, 2019

BACKGROUND

Spinal Muscular Atrophy

Spinal muscular atrophy is a genetic disease affecting the part of the nervous system that controls voluntary muscle movement. Specifically, it is a motor neuron disease that involves the loss of nerve cells in the spinal cord that may affect a person's ability to walk, eat, or breathe, among other things. The earlier the age of onset, the greater the effect the disease has on motor function.

Related Act

PA 19-117, § 148, expands the state's newborn screening program to include any disorder listed on the federal Recommended Uniform Screening Panel, subject to the Office of Policy and Management secretary's approval.