



100TH GENERAL ASSEMBLY

State of Illinois

2017 and 2018

HB4142

Introduced 10/26/2017, by Rep. Mark Batinick - Daniel Swanson
- Laura Fine - Silvana Tabares

SYNOPSIS AS INTRODUCED:

410 ILCS 240/3.35 new

Amends the Newborn Metabolic Screening Act. Requires the Department of Public Health to provide all newborns and infants within 12 months of birth with screening tests for the presence of spinal muscular atrophy. Provides that the testing shall begin within 12 months of the occurrence of specified events. Provides that the Department is authorized to implement an additional fee for the screening prior to beginning the testing in order to accumulate the resources for start-up and other costs associated with implementation of the screening and thereafter to support the costs associated with screening and follow-up programs for spinal muscular atrophy.

LRB100 14281 MJP 29055 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

1 AN ACT concerning health.

2 **Be it enacted by the People of the State of Illinois,**
3 **represented in the General Assembly:**

4 Section 5. The Newborn Metabolic Screening Act is amended
5 by adding Section 3.35 as follows:

6 (410 ILCS 240/3.35 new)

7 Sec. 3.35. Spinal muscular atrophy. In accordance with the
8 timetable specified in this Section, the Department shall
9 provide all newborns and infants within 12 months of birth with
10 screening tests for the presence of spinal muscular atrophy.
11 The testing shall begin within 12 months following the
12 occurrence of all of the following:

13 (1) the establishment and verification of relevant and
14 appropriate performance specifications as defined under
15 the federal Clinical Laboratory Improvement Amendments and
16 regulations thereunder for Federal Drug
17 Administration-cleared or in-house developed methods,
18 performed under an institutional review board approved
19 protocol, if required;

20 (2) the availability of quality assurance testing and
21 comparative threshold values for the spinal muscular
22 atrophy screening test;

23 (3) the acquisition and installment by the Department

1 of the equipment necessary to implement the initial pilot
2 and statewide volume of screening tests for spinal muscular
3 atrophy;

4 (4) the establishment of precise threshold values
5 ensuring defined spinal muscular atrophy identification
6 for the screening test;

7 (5) the authentication of pilot testing achieving each
8 milestone described in items (1) through (4) of this
9 Section for the spinal muscular atrophy screening test; and

10 (6) the authentication of achieving the potential of
11 high throughput standards for statewide volume of the
12 spinal muscular atrophy screening test concomitant with
13 each milestone described in items (1) through (4) of this
14 Section.

15 The Department is authorized to implement an additional fee
16 for the screening prior to beginning the testing in order to
17 accumulate the resources for start-up and other costs
18 associated with implementation of the screening and thereafter
19 to support the costs associated with screening and follow-up
20 programs for spinal muscular atrophy.