

HB4896



96TH GENERAL ASSEMBLY

State of Illinois

2009 and 2010

HB4896

Introduced 1/15/2010, by Rep. Raymond Poe

SYNOPSIS AS INTRODUCED:

410 ILCS 240/2

from Ch. 111 1/2, par. 4904

Amends the Newborn Metabolic Screening Act. Provides that the Metabolic Screening and Treatment Fund is not subject to sweeps, administrative charges, or charge-backs. Effective immediately.

LRB096 16094 HLH 31343 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

1 AN ACT concerning State government.

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 changing Section 2 as follows:

6 (410 ILCS 240/2) (from Ch. 111 1/2, par. 4904)

7 Sec. 2. The Department of Public Health shall administer
8 the provisions of this Act and shall:

9 (a) Institute and carry on an intensive educational program
10 among physicians, hospitals, public health nurses and the
11 public concerning the diseases phenylketonuria,
12 hypothyroidism, galactosemia and other metabolic diseases.
13 This educational program shall include information about the
14 nature of the diseases and examinations for the detection of
15 the diseases in early infancy in order that measures may be
16 taken to prevent the mental retardation resulting from the
17 diseases.

18 (a-5) Beginning July 1, 2002, provide all newborns with
19 expanded screening tests for the presence of genetic,
20 endocrine, or other metabolic disorders, including
21 phenylketonuria, galactosemia, hypothyroidism, congenital
22 adrenal hyperplasia, biotinidase deficiency, and sickling
23 disorders, as well as other amino acid disorders, organic acid

1 disorders, fatty acid oxidation disorders, and other
2 abnormalities detectable through the use of a tandem mass
3 spectrometer. If by July 1, 2002, the Department is unable to
4 provide expanded screening using the State Laboratory, it shall
5 temporarily provide such screening through an accredited
6 laboratory selected by the Department until the Department has
7 the capacity to provide screening through the State Laboratory.
8 If expanded screening is provided on a temporary basis through
9 an accredited laboratory, the Department shall substitute the
10 fee charged by the accredited laboratory, plus a 5% surcharge
11 for documentation and handling, for the fee authorized in
12 subsection (e) of this Section.

13 (a-6) In accordance with the timetable specified in this
14 subsection, provide all newborns with expanded screening tests
15 for the presence of certain Lysosomal Storage Disorders known
16 as Krabbe, Pompe, Gaucher, Fabry, and Niemann-Pick. The testing
17 shall begin within 6 months following the occurrence of all of
18 the following:

19 (i) the registration with the federal Food and Drug
20 Administration of the necessary reagents;

21 (ii) the availability of the necessary reagents from
22 the Centers for Disease Control and Prevention;

23 (iii) the availability of quality assurance testing
24 methodology for these processes; and

25 (iv) the acquisition and installment by the Department
26 of the equipment necessary to implement the expanded

1 screening tests.

2 It is the goal of this amendatory Act of the 95th General
3 Assembly that the expanded screening for the specified
4 Lysosomal Storage Disorders begins within 3 years after the
5 effective date of this Act. The Department is authorized to
6 implement an additional fee for the screening prior to
7 beginning the testing in order to accumulate the resources for
8 start-up and other costs associated with implementation of the
9 screening and thereafter to support the costs associated with
10 screening and follow-up programs for the specified Lysosomal
11 Storage Disorders.

12 (b) Maintain a registry of cases including information of
13 importance for the purpose of follow-up services to prevent
14 mental retardation.

15 (c) Supply the necessary metabolic treatment formulas
16 where practicable for diagnosed cases of amino acid metabolism
17 disorders, including phenylketonuria, organic acid disorders,
18 and fatty acid oxidation disorders for as long as medically
19 indicated, when the product is not available through other
20 State agencies.

21 (d) Arrange for or provide public health nursing, nutrition
22 and social services and clinical consultation as indicated.

23 (e) Require that all specimens collected pursuant to this
24 Act or the rules and regulations promulgated hereunder be
25 submitted for testing to the nearest Department of Public
26 Health laboratory designated to perform such tests. The

1 Department may develop a reasonable fee structure and may levy
2 fees according to such structure to cover the cost of providing
3 this testing service. Fees collected from the provision of this
4 testing service shall be placed in a special fund in the State
5 Treasury, hereafter known as the Metabolic Screening and
6 Treatment Fund. Other State and federal funds for expenses
7 related to metabolic screening, follow-up and treatment
8 programs may also be placed in such Fund. Moneys shall be
9 appropriated from such Fund to the Department of Public Health
10 solely for the purposes of providing metabolic screening,
11 follow-up and treatment programs. The Metabolic Screening and
12 Treatment Fund is not subject to sweeps, administrative
13 charges, or charge-backs, including but not limited to those
14 authorized under Section 8h of the State Finance Act, or any
15 other fiscal or budgetary maneuver that would in any way
16 transfer any funds from the Metabolic Screening and Treatment
17 Fund into any other fund of the State. Nothing in this Act
18 shall be construed to prohibit any licensed medical facility
19 from collecting additional specimens for testing for metabolic
20 or neonatal diseases or any other diseases or conditions, as it
21 deems fit. Any person violating the provisions of this
22 subsection (e) is guilty of a petty offense.

23 (Source: P.A. 95-695, eff. 11-5-07.)

24 Section 99. Effective date. This Act takes effect upon
25 becoming law.