

1 AN ACT concerning public 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 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 (a-10) Beginning 90 days after the effective date of this
13 amendatory Act of the 97th General Assembly, provide newborns
14 with expanded screening tests for the presence of
15 Mucopolysaccharidosis I (Hurler disease) and
16 Mucopolysaccharidosis II (Hunter's disease).

17 (a-15) Beginning 180 days after the effective date of this
18 amendatory Act of the 97th General Assembly, provide all
19 newborns with expanded screening tests for the presence of
20 Severe Combined Immunodeficiency Syndrome (SCIDS). If the
21 Department is unable to provide expanded screening for SCIDS
22 using the State Laboratory within 180 days after the effective
23 date of this amendatory Act, then it shall temporarily provide
24 the screening through an accredited laboratory selected by the
25 Department until the Department has the capacity to provide
26 screening through the State Laboratory. If expanded screening

1 is provided on a temporary basis through an accredited
2 laboratory, then the Department shall substitute the fee
3 charged by the accredited laboratory, plus a 5% surcharge for
4 documentation and handling, for the fee authorized in
5 subsection (e) of this Section.

6 (b) Maintain a registry of cases including information of
7 importance for the purpose of follow-up services to prevent
8 mental retardation.

9 (c) Supply the necessary metabolic treatment formulas
10 where practicable for diagnosed cases of amino acid metabolism
11 disorders, including phenylketonuria, organic acid disorders,
12 and fatty acid oxidation disorders for as long as medically
13 indicated, when the product is not available through other
14 State agencies.

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

17 (e) Require that all specimens collected pursuant to this
18 Act or the rules and regulations promulgated hereunder be
19 submitted for testing to the nearest Department of Public
20 Health laboratory designated to perform such tests. The
21 Department may develop a reasonable fee structure and may levy
22 fees according to such structure to cover the cost of providing
23 this testing service. Fees collected from the provision of this
24 testing service shall be placed in a special fund in the State
25 Treasury, hereafter known as the Metabolic Screening and
26 Treatment Fund. Other State and federal funds for expenses

1 related to metabolic screening, follow-up and treatment
2 programs may also be placed in such Fund. Moneys shall be
3 appropriated from such Fund to the Department of Public Health
4 solely for the purposes of providing metabolic screening,
5 follow-up and treatment programs. Nothing in this Act shall be
6 construed to prohibit any licensed medical facility from
7 collecting additional specimens for testing for metabolic or
8 neonatal diseases or any other diseases or conditions, as it
9 deems fit. Any person violating the provisions of this
10 subsection (e) is guilty of a petty offense.

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

12 Section 99. Effective date. This Act takes effect upon
13 becoming law.