

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 administrative charges, or  
13 charge-backs, including but not limited to those authorized  
14 under Section 8h of the State Finance Act. Nothing in this Act  
15 shall be construed to prohibit any licensed medical facility  
16 from collecting additional specimens for testing for metabolic  
17 or neonatal diseases or any other diseases or conditions, as it  
18 deems fit. Any person violating the provisions of this  
19 subsection (e) is guilty of a petty offense.

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

21 Section 99. Effective date. This Act takes effect upon  
22 becoming law.