

1 AN ACT in relation to public health.

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

4 Section 5. The Phenylketonuria Testing Act is amended by
5 adding Section 1.5 and changing Section 2 as follows:

6 (410 ILCS 240/1.5 new)

7 Sec. 1.5. Definitions. In this Act:

8 "Accredited laboratory" means any laboratory that holds a
9 valid certificate issued under the Clinical Laboratory
10 Improvement Amendments of 1988, 102 Stat. 2903, 42 U.S.C.
11 263a, as amended, and that reports its screening results by
12 using normal pediatric reference ranges.

13 "Expanded screening" means screening for genetic and
14 metabolic disorders, including but not limited to amino acid
15 disorders, organic acid disorders, fatty acid oxidation
16 disorders, and other abnormal profiles, in newborn infants
17 that can be detected through the use of a tandem mass
18 spectrometer.

19 "Tandem mass spectrometer" means an analytical instrument
20 used to detect numerous genetic and metabolic disorders at
21 one time.

22 (410 ILCS 240/2) (from Ch. 111 1/2, par. 4904)

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

25 (a) Institute and carry on an intensive educational
26 program among physicians, hospitals, public health nurses and
27 the public concerning the diseases phenylketonuria,
28 hypothyroidism, galactosemia and other metabolic diseases.
29 This educational program shall include information about the
30 nature of the diseases and examinations for the detection of

1 the diseases in early infancy in order that measures may be
2 taken to prevent the mental retardation resulting from the
3 diseases.

4 (a-5) Beginning July 1, 2002, provide all newborns with
5 expanded screening tests for the presence of genetic,
6 endocrine, or other metabolic disorders, including
7 phenylketonuria, galactosemia, hypothyroidism, congenital
8 adrenal hyperplasia, biotinidase deficiency, and sickling
9 disorders, as well as other amino acid disorders, organic
10 acid disorders, fatty acid oxidation disorders, and other
11 abnormalities detectable through the use of a tandem mass
12 spectrometer. If by July 1, 2002, the Department is unable to
13 provide expanded screening using the State Laboratory, it
14 shall temporarily provide such screening through an
15 accredited laboratory selected by the Department until the
16 Department has the capacity to provide screening through the
17 State Laboratory. If expanded screening is provided on a
18 temporary basis through an accredited laboratory, the
19 Department shall substitute the fee charged by the accredited
20 laboratory, plus a 5% surcharge for documentation and
21 handling, for the fee authorized in subsection (e) of this
22 Section.

23 (b) Maintain a registry of cases including information
24 of importance for the purpose of follow-up services to
25 prevent mental retardation.

26 (c) Supply the necessary treatment product where
27 practicable for diagnosed cases for as long as medically
28 indicated, when the product is not available through other
29 State agencies.

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

33 (e) Require that all specimens collected pursuant to
34 this Act or the rules and regulations promulgated hereunder

1 be submitted for testing to the nearest Department of Public
2 Health laboratory designated to perform such tests. The
3 Department may develop a reasonable fee structure and may
4 levy fees according to such structure to cover the cost of
5 providing this testing service. Fees collected from the
6 provision of this testing service shall be placed in a
7 special fund in the State Treasury, hereafter known as the
8 Metabolic Screening and Treatment Fund. Other State and
9 federal funds for expenses related to metabolic screening,
10 follow-up and treatment programs may also be placed in such
11 Fund. Moneys shall be appropriated from such Fund to the
12 Department of Public Health solely for the purposes of
13 providing metabolic screening, follow-up and treatment
14 programs. Nothing in this Act shall be construed to prohibit
15 any licensed medical facility from collecting additional
16 specimens for testing for metabolic or neonatal diseases or
17 any other diseases or conditions, as it deems fit. Any person
18 violating the provisions of this subsection (e) is guilty of
19 a petty offense.

20 (Source: P.A. 83-87.)

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