

SB1566



95TH GENERAL ASSEMBLY

State of Illinois

2007 and 2008

SB1566

Introduced 2/9/2007, by Sen. Dale A. Righter

SYNOPSIS AS INTRODUCED:

New Act
30 ILCS 105/8h
410 ILCS 240/2

from Ch. 111 1/2, par. 4904

Creates the Genetic and Metabolic Diseases Advisory Committee Act. Provides that the Director of Public Health shall create the Genetic and Metabolic Diseases Advisory Committee to advise the Department of Public Health regarding issues relevant to newborn screenings of metabolic diseases. Amends the State Finance Act to exempt the Metabolic Screening and Treatment Fund from transfers made by the Governor to the General Revenue Fund. Amends the Phenylketonuria Testing Act. Provides that beginning July 1, 2008, the Department of Public Health shall provide all newborns with expanded screening tests for the presence of Lysosomal Storage Disorders known as Krabbe, Pompe, Gaucher, Fabry, and Niemann-Pick. Effective immediately.

LRB095 10699 KBJ 30931 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

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 1. Short title. This Act may be cited as the
5 Genetic and Metabolic Diseases Advisory Committee Act.

6 Section 5. Genetic and Metabolic Diseases Advisory
7 Committee.

8 (a) The Director of Public Health shall create the Genetic
9 and Metabolic Diseases Advisory Committee to advise the
10 Department of Public Health regarding issues relevant to
11 newborn screenings of metabolic diseases.

12 (b) The purposes of Metabolic Diseases Advisory Committee
13 are all of the following:

14 (1) Advise the Department regarding issues relevant to
15 its Genetics Program.

16 (2) Advise the Department regarding optimal laboratory
17 methodologies for screening of the targeted conditions.

18 (3) Recommend to the Department consultants who are
19 qualified to diagnose a condition detected by screening,
20 provide management of care, and genetic counseling for the
21 family.

22 (4) Monitor the incidence of each condition for which
23 newborn screening is done, evaluate the effects of

1 treatment and genetic counseling, and provide advice on
2 disorders to be included in newborn screening panel.

3 (5) Advise the Department on educational programs for
4 professionals and the general public.

5 (6) Advise the Department on new developments and areas
6 of interest in relation to the Genetics Program.

7 (7) Any other matter deemed appropriate by the
8 Committee and the Director.

9 (c) The Committee shall consist of 20 members appointed by
10 the Director of Public Health and approved by the Governor.
11 Membership shall include physicians, geneticists, nurses,
12 nutritionists, and other allied health professionals, as well
13 as patients and parents. The term of membership shall be up to
14 3 years. A member may be appointed for 2 consecutive terms.
15 After 2 terms, a member must be off the Committee for a least
16 one year. Members of the Committee must serve on a subcommittee
17 or a special project. Ex-officio members may be appointed and
18 may include the following:

19 (1) The Chief of the Division of Children's Health and
20 Safety.

21 (2) The Director of the Division of Specialized Care
22 for Children.

23 (3) The Administrator of the Genetics Program.

24 (4) The Chief of the Metabolic Section of the Division
25 of Laboratories.

26 (5) The President of the Genetics Task Force of

1 Illinois, Inc.

2 (6) Representation from patient and parent support or
3 advocacy groups.

4 Ex-officio members shall not have voting privileges.

5 Section 10. The State Finance Act is amended by changing
6 Section 8h as follows:

7 (30 ILCS 105/8h)

8 Sec. 8h. Transfers to General Revenue Fund.

9 (a) Except as otherwise provided in this Section and
10 Section 8n of this Act, and ~~(e), (d), or (e)~~, notwithstanding
11 any other State law to the contrary, the Governor may, through
12 June 30, 2007, from time to time direct the State Treasurer and
13 Comptroller to transfer a specified sum from any fund held by
14 the State Treasurer to the General Revenue Fund in order to
15 help defray the State's operating costs for the fiscal year.
16 The total transfer under this Section from any fund in any
17 fiscal year shall not exceed the lesser of (i) 8% of the
18 revenues to be deposited into the fund during that fiscal year
19 or (ii) an amount that leaves a remaining fund balance of 25%
20 of the July 1 fund balance of that fiscal year. In fiscal year
21 2005 only, prior to calculating the July 1, 2004 final
22 balances, the Governor may calculate and direct the State
23 Treasurer with the Comptroller to transfer additional amounts
24 determined by applying the formula authorized in Public Act

1 93-839 to the funds balances on July 1, 2003. No transfer may
2 be made from a fund under this Section that would have the
3 effect of reducing the available balance in the fund to an
4 amount less than the amount remaining unexpended and unreserved
5 from the total appropriation from that fund estimated to be
6 expended for that fiscal year. This Section does not apply to
7 any funds that are restricted by federal law to a specific use,
8 to any funds in the Motor Fuel Tax Fund, the Intercity
9 Passenger Rail Fund, the Hospital Provider Fund, the Medicaid
10 Provider Relief Fund, the Teacher Health Insurance Security
11 Fund, the Reviewing Court Alternative Dispute Resolution Fund,
12 the Voters' Guide Fund, the Foreign Language Interpreter Fund,
13 the Lawyers' Assistance Program Fund, the Supreme Court Federal
14 Projects Fund, the Supreme Court Special State Projects Fund,
15 the Supplemental Low-Income Energy Assistance Fund, the Good
16 Samaritan Energy Trust Fund, the Low-Level Radioactive Waste
17 Facility Development and Operation Fund, the Horse Racing
18 Equity Trust Fund, the Metabolic Screening and Treatment Fund,
19 or the Hospital Basic Services Preservation Fund, or to any
20 funds to which subsection (f) of Section 20-40 of the Nursing
21 and Advanced Practice Nursing Act applies. No transfers may be
22 made under this Section from the Pet Population Control Fund.
23 Notwithstanding any other provision of this Section, for fiscal
24 year 2004, the total transfer under this Section from the Road
25 Fund or the State Construction Account Fund shall not exceed
26 the lesser of (i) 5% of the revenues to be deposited into the

1 fund during that fiscal year or (ii) 25% of the beginning
2 balance in the fund. For fiscal year 2005 through fiscal year
3 2007, no amounts may be transferred under this Section from the
4 Road Fund, the State Construction Account Fund, the Criminal
5 Justice Information Systems Trust Fund, the Wireless Service
6 Emergency Fund, or the Mandatory Arbitration Fund.

7 In determining the available balance in a fund, the
8 Governor may include receipts, transfers into the fund, and
9 other resources anticipated to be available in the fund in that
10 fiscal year.

11 The State Treasurer and Comptroller shall transfer the
12 amounts designated under this Section as soon as may be
13 practicable after receiving the direction to transfer from the
14 Governor.

15 (a-5) Transfers directed to be made under this Section on
16 or before February 28, 2006 that are still pending on May 19,
17 2006 (the effective date of Public Act 94-774) ~~this amendatory~~
18 ~~Act of the 94th General Assembly~~ shall be redirected as
19 provided in Section 8n of this Act.

20 (b) This Section does not apply to: (i) the Ticket For The
21 Cure Fund; (ii) any fund established under the Community Senior
22 Services and Resources Act; or (iii) on or after January 1,
23 2006 (the effective date of Public Act 94-511), the Child Labor
24 and Day and Temporary Labor Enforcement Fund.

25 (c) This Section does not apply to the Demutualization
26 Trust Fund established under the Uniform Disposition of

1 Unclaimed Property Act.

2 (d) This Section does not apply to moneys set aside in the
3 Illinois State Podiatric Disciplinary Fund for podiatric
4 scholarships and residency programs under the Podiatric
5 Scholarship and Residency Act.

6 (e) Subsection (a) does not apply to, and no transfer may
7 be made under this Section from, the Pension Stabilization
8 Fund.

9 (Source: P.A. 93-32, eff. 6-20-03; 93-659, eff. 2-3-04; 93-674,
10 eff. 6-10-04; 93-714, eff. 7-12-04; 93-801, eff. 7-22-04;
11 93-839, eff. 7-30-04; 93-1054, eff. 11-18-04; 93-1067, eff.
12 1-15-05; 94-91, eff. 7-1-05; 94-120, eff. 7-6-05; 94-511, eff.
13 1-1-06; 94-535, eff. 8-10-05; 94-639, eff. 8-22-05; 94-645,
14 eff. 8-22-05; 94-648, eff. 1-1-06; 94-686, eff. 11-2-05;
15 94-691, eff. 11-2-05; 94-726, eff. 1-20-06; 94-773, eff.
16 5-18-06; 94-774, eff. 5-19-06; 94-804, eff. 5-26-06; 94-839,
17 eff. 6-6-06; revised 6-19-06.)

18 Section 15. The Phenylketonuria Testing Act is amended by
19 changing Section 2 as follows:

20 (410 ILCS 240/2) (from Ch. 111 1/2, par. 4904)

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

23 (a) Institute and carry on an intensive educational program
24 among physicians, hospitals, public health nurses and the

1 public concerning the diseases phenylketonuria,
2 hypothyroidism, galactosemia and other metabolic diseases.
3 This educational program shall include information about the
4 nature of the diseases and examinations for the detection of
5 the diseases in early infancy in order that measures may be
6 taken to prevent the mental retardation resulting from the
7 diseases.

8 (a-5) Beginning July 1, 2002, provide all newborns with
9 expanded screening tests for the presence of genetic,
10 endocrine, or other metabolic disorders, including
11 phenylketonuria, galactosemia, hypothyroidism, congenital
12 adrenal hyperplasia, biotinidase deficiency, and sickling
13 disorders, as well as other amino acid disorders, organic acid
14 disorders, fatty acid oxidation disorders, and other
15 abnormalities detectable through the use of a tandem mass
16 spectrometer. Beginning July 1, 2008, provide all newborns with
17 expanded screening tests for the presence of Lysosomal Storage
18 Disorders known as Krabbe, Pompe, Gaucher, Fabry, and
19 Niemann-Pick. If by July 1, 2002, the Department is unable to
20 provide expanded screening using the State Laboratory, it shall
21 temporarily provide such screening through an accredited
22 laboratory selected by the Department until the Department has
23 the capacity to provide screening through the State Laboratory.
24 If expanded screening is provided on a temporary basis through
25 an accredited laboratory, the Department shall substitute the
26 fee charged by the accredited laboratory, plus a 5% surcharge

1 for documentation and handling, for the fee authorized in
2 subsection (e) of this Section.

3 (b) Maintain a registry of cases including information of
4 importance for the purpose of follow-up services to prevent
5 mental retardation.

6 (c) Supply the necessary treatment product where
7 practicable for diagnosed cases for as long as medically
8 indicated, when the product is not available through other
9 State agencies.

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

12 (e) Require that all specimens collected pursuant to this
13 Act or the rules and regulations promulgated hereunder be
14 submitted for testing to the nearest Department of Public
15 Health laboratory designated to perform such tests. The
16 Department may develop a reasonable fee structure and may levy
17 fees according to such structure to cover the cost of providing
18 this testing service. Fees collected from the provision of this
19 testing service shall be placed in a special fund in the State
20 Treasury, hereafter known as the Metabolic Screening and
21 Treatment Fund. Other State and federal funds for expenses
22 related to metabolic screening, follow-up and treatment
23 programs may also be placed in such Fund. Moneys shall be
24 appropriated from such Fund to the Department of Public Health
25 solely for the purposes of providing metabolic screening,
26 follow-up and treatment programs. Nothing in this Act shall be

1 construed to prohibit any licensed medical facility from
2 collecting additional specimens for testing for metabolic or
3 neonatal diseases or any other diseases or conditions, as it
4 deems fit. Any person violating the provisions of this
5 subsection (e) is guilty of a petty offense.

6 (Source: P.A. 92-701, eff. 7-19-02.)

7 Section 99. Effective date. This Act takes effect upon
8 becoming law.