

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. Membership shall include
11 physicians, geneticists, nurses, nutritionists, and other
12 allied health professionals, as well as patients and parents.
13 Ex-officio members may be appointed, but shall not have voting
14 privileges.

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

17 (30 ILCS 105/8h)

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

19 (a) Except as otherwise provided in this Section and
20 Section 8n of this Act, and ~~(e), (d), or (e)~~, notwithstanding
21 any other State law to the contrary, the Governor may, through
22 June 30, 2007, from time to time direct the State Treasurer and
23 Comptroller to transfer a specified sum from any fund held by
24 the State Treasurer to the General Revenue Fund in order to

1 help defray the State's operating costs for the fiscal year.
2 The total transfer under this Section from any fund in any
3 fiscal year shall not exceed the lesser of (i) 8% of the
4 revenues to be deposited into the fund during that fiscal year
5 or (ii) an amount that leaves a remaining fund balance of 25%
6 of the July 1 fund balance of that fiscal year. In fiscal year
7 2005 only, prior to calculating the July 1, 2004 final
8 balances, the Governor may calculate and direct the State
9 Treasurer with the Comptroller to transfer additional amounts
10 determined by applying the formula authorized in Public Act
11 93-839 to the funds balances on July 1, 2003. No transfer may
12 be made from a fund under this Section that would have the
13 effect of reducing the available balance in the fund to an
14 amount less than the amount remaining unexpended and unreserved
15 from the total appropriation from that fund estimated to be
16 expended for that fiscal year. This Section does not apply to
17 any funds that are restricted by federal law to a specific use,
18 to any funds in the Motor Fuel Tax Fund, the Intercity
19 Passenger Rail Fund, the Hospital Provider Fund, the Medicaid
20 Provider Relief Fund, the Teacher Health Insurance Security
21 Fund, the Reviewing Court Alternative Dispute Resolution Fund,
22 the Voters' Guide Fund, the Foreign Language Interpreter Fund,
23 the Lawyers' Assistance Program Fund, the Supreme Court Federal
24 Projects Fund, the Supreme Court Special State Projects Fund,
25 the Supplemental Low-Income Energy Assistance Fund, the Good
26 Samaritan Energy Trust Fund, the Low-Level Radioactive Waste

1 Facility Development and Operation Fund, the Horse Racing
2 Equity Trust Fund, the Metabolic Screening and Treatment Fund,
3 or the Hospital Basic Services Preservation Fund, or to any
4 funds to which subsection (f) of Section 20-40 of the Nursing
5 and Advanced Practice Nursing Act applies. No transfers may be
6 made under this Section from the Pet Population Control Fund.
7 Notwithstanding any other provision of this Section, for fiscal
8 year 2004, the total transfer under this Section from the Road
9 Fund or the State Construction Account Fund shall not exceed
10 the lesser of (i) 5% of the revenues to be deposited into the
11 fund during that fiscal year or (ii) 25% of the beginning
12 balance in the fund. For fiscal year 2005 through fiscal year
13 2007, no amounts may be transferred under this Section from the
14 Road Fund, the State Construction Account Fund, the Criminal
15 Justice Information Systems Trust Fund, the Wireless Service
16 Emergency Fund, or the Mandatory Arbitration Fund.

17 In determining the available balance in a fund, the
18 Governor may include receipts, transfers into the fund, and
19 other resources anticipated to be available in the fund in that
20 fiscal year.

21 The State Treasurer and Comptroller shall transfer the
22 amounts designated under this Section as soon as may be
23 practicable after receiving the direction to transfer from the
24 Governor.

25 (a-5) Transfers directed to be made under this Section on
26 or before February 28, 2006 that are still pending on May 19,

1 2006 (the effective date of Public Act 94-774) ~~this amendatory~~
2 ~~Act of the 94th General Assembly~~ shall be redirected as
3 provided in Section 8n of this Act.

4 (b) This Section does not apply to: (i) the Ticket For The
5 Cure Fund; (ii) any fund established under the Community Senior
6 Services and Resources Act; or (iii) on or after January 1,
7 2006 (the effective date of Public Act 94-511), the Child Labor
8 and Day and Temporary Labor Enforcement Fund.

9 (c) This Section does not apply to the Demutualization
10 Trust Fund established under the Uniform Disposition of
11 Unclaimed Property Act.

12 (d) This Section does not apply to moneys set aside in the
13 Illinois State Podiatric Disciplinary Fund for podiatric
14 scholarships and residency programs under the Podiatric
15 Scholarship and Residency Act.

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

19 (Source: P.A. 93-32, eff. 6-20-03; 93-659, eff. 2-3-04; 93-674,
20 eff. 6-10-04; 93-714, eff. 7-12-04; 93-801, eff. 7-22-04;
21 93-839, eff. 7-30-04; 93-1054, eff. 11-18-04; 93-1067, eff.
22 1-15-05; 94-91, eff. 7-1-05; 94-120, eff. 7-6-05; 94-511, eff.
23 1-1-06; 94-535, eff. 8-10-05; 94-639, eff. 8-22-05; 94-645,
24 eff. 8-22-05; 94-648, eff. 1-1-06; 94-686, eff. 11-2-05;
25 94-691, eff. 11-2-05; 94-726, eff. 1-20-06; 94-773, eff.
26 5-18-06; 94-774, eff. 5-19-06; 94-804, eff. 5-26-06; 94-839,

1 eff. 6-6-06; revised 6-19-06.)

2 Section 15. The Phenylketonuria Testing Act is amended by
3 changing Sections 0.01 and 2 as follows:

4 (410 ILCS 240/0.01) (from Ch. 111 1/2, par. 4902.9)

5 Sec. 0.01. Short title. This Act may be cited as the
6 Newborn Metabolic Screening ~~Phenylketonuria Testing~~ Act.

7 (Source: P.A. 86-1324.)

8 (410 ILCS 240/2) (from Ch. 111 1/2, par. 4904)

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

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

20 (a-5) Beginning July 1, 2002, provide all newborns with
21 expanded screening tests for the presence of genetic,
22 endocrine, or other metabolic disorders, including
23 phenylketonuria, galactosemia, hypothyroidism, congenital

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

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

21 (i) the registration with the federal Food and Drug
22 Administration of the necessary reagents;

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

25 (iii) the availability of quality assurance testing
26 methodology for these processes; and

1 (iv) the acquisition and installment by the Department
2 of the equipment necessary to implement the expanded
3 screening tests.

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

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

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

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

25 (e) Require that all specimens collected pursuant to this
26 Act or the rules and regulations promulgated hereunder be

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

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

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