

AN ACT concerning public health.

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

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

Section 5. Genetic and Metabolic Diseases Advisory Committee.

(a) 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.

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

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

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

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

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

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

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

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

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

(c) The Committee shall consist of 20 members appointed by the Director of Public Health. Membership shall include physicians, geneticists, nurses, nutritionists, and other allied health professionals, as well as patients and parents. Ex-officio members may be appointed, but shall not have voting privileges.

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

(30 ILCS 105/8h)

Sec. 8h. Transfers to General Revenue Fund.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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