



**Adopted in House Comm. on May 08, 2007**

09500SB1566ham001

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1 AMENDMENT TO SENATE BILL 1566

2 AMENDMENT NO. \_\_\_\_\_. Amend Senate Bill 1566 by replacing  
3 everything after the enacting clause with the following:

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

1 methodologies for screening of the targeted conditions.

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

6 (4) Monitor the incidence of each condition for which  
7 newborn screening is done, evaluate the effects of  
8 treatment and genetic counseling, and provide advice on  
9 disorders to be included in newborn screening panel.

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

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

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

16 (c) The Committee shall consist of 20 members appointed by  
17 the Director of Public Health. Membership shall include  
18 physicians, geneticists, nurses, nutritionists, and other  
19 allied health professionals, as well as patients and parents.

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

22 (30 ILCS 105/8h)

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

24 (a) Except as otherwise provided in this Section and

1 Section 8n of this Act, and ~~(e), (d), or (e)~~, notwithstanding  
2 any other State law to the contrary, the Governor may, through  
3 June 30, 2007, from time to time direct the State Treasurer and  
4 Comptroller to transfer a specified sum from any fund held by  
5 the State Treasurer to the General Revenue Fund in order to  
6 help defray the State's operating costs for the fiscal year.  
7 The total transfer under this Section from any fund in any  
8 fiscal year shall not exceed the lesser of (i) 8% of the  
9 revenues to be deposited into the fund during that fiscal year  
10 or (ii) an amount that leaves a remaining fund balance of 25%  
11 of the July 1 fund balance of that fiscal year. In fiscal year  
12 2005 only, prior to calculating the July 1, 2004 final  
13 balances, the Governor may calculate and direct the State  
14 Treasurer with the Comptroller to transfer additional amounts  
15 determined by applying the formula authorized in Public Act  
16 93-839 to the funds balances on July 1, 2003. No transfer may  
17 be made from a fund under this Section that would have the  
18 effect of reducing the available balance in the fund to an  
19 amount less than the amount remaining unexpended and unreserved  
20 from the total appropriation from that fund estimated to be  
21 expended for that fiscal year. This Section does not apply to  
22 any funds that are restricted by federal law to a specific use,  
23 to any funds in the Motor Fuel Tax Fund, the Intercity  
24 Passenger Rail Fund, the Hospital Provider Fund, the Medicaid  
25 Provider Relief Fund, the Teacher Health Insurance Security  
26 Fund, the Reviewing Court Alternative Dispute Resolution Fund,

1 the Voters' Guide Fund, the Foreign Language Interpreter Fund,  
2 the Lawyers' Assistance Program Fund, the Supreme Court Federal  
3 Projects Fund, the Supreme Court Special State Projects Fund,  
4 the Supplemental Low-Income Energy Assistance Fund, the Good  
5 Samaritan Energy Trust Fund, the Low-Level Radioactive Waste  
6 Facility Development and Operation Fund, the Horse Racing  
7 Equity Trust Fund, the Metabolic Screening and Treatment Fund,  
8 or the Hospital Basic Services Preservation Fund, or to any  
9 funds to which subsection (f) of Section 20-40 of the Nursing  
10 and Advanced Practice Nursing Act applies. No transfers may be  
11 made under this Section from the Pet Population Control Fund.  
12 Notwithstanding any other provision of this Section, for fiscal  
13 year 2004, the total transfer under this Section from the Road  
14 Fund or the State Construction Account Fund shall not exceed  
15 the lesser of (i) 5% of the revenues to be deposited into the  
16 fund during that fiscal year or (ii) 25% of the beginning  
17 balance in the fund. For fiscal year 2005 through fiscal year  
18 2007, no amounts may be transferred under this Section from the  
19 Road Fund, the State Construction Account Fund, the Criminal  
20 Justice Information Systems Trust Fund, the Wireless Service  
21 Emergency Fund, or the Mandatory Arbitration Fund.

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

26 The State Treasurer and Comptroller shall transfer the

1 amounts designated under this Section as soon as may be  
2 practicable after receiving the direction to transfer from the  
3 Governor.

4 (a-5) Transfers directed to be made under this Section on  
5 or before February 28, 2006 that are still pending on May 19,  
6 2006 (the effective date of Public Act 94-774) ~~this amendatory~~  
7 ~~Act of the 94th General Assembly~~ shall be redirected as  
8 provided in Section 8n of this Act.

9 (b) This Section does not apply to: (i) the Ticket For The  
10 Cure Fund; (ii) any fund established under the Community Senior  
11 Services and Resources Act; or (iii) on or after January 1,  
12 2006 (the effective date of Public Act 94-511), the Child Labor  
13 and Day and Temporary Labor Enforcement Fund.

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

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

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

24 (Source: P.A. 93-32, eff. 6-20-03; 93-659, eff. 2-3-04; 93-674,  
25 eff. 6-10-04; 93-714, eff. 7-12-04; 93-801, eff. 7-22-04;  
26 93-839, eff. 7-30-04; 93-1054, eff. 11-18-04; 93-1067, eff.

1 1-15-05; 94-91, eff. 7-1-05; 94-120, eff. 7-6-05; 94-511, eff.  
2 1-1-06; 94-535, eff. 8-10-05; 94-639, eff. 8-22-05; 94-645,  
3 eff. 8-22-05; 94-648, eff. 1-1-06; 94-686, eff. 11-2-05;  
4 94-691, eff. 11-2-05; 94-726, eff. 1-20-06; 94-773, eff.  
5 5-18-06; 94-774, eff. 5-19-06; 94-804, eff. 5-26-06; 94-839,  
6 eff. 6-6-06; revised 6-19-06.)

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

9 (410 ILCS 240/0.01) (from Ch. 111 1/2, par. 4902.9)

10 Sec. 0.01. Short title. This Act may be cited as the  
11 Metabolic Disorder ~~Phenylketonuria~~ Testing Act.

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

13 (410 ILCS 240/2) (from Ch. 111 1/2, par. 4904)

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

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

1 diseases.

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

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

26 (i) the registration with the federal Food and Drug

1       Administration of the necessary reagents;

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

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

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

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

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

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



1 State agencies.

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

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

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

25 Section 99. Effective date. This Act takes effect upon

1 becoming law.".