

1                                   AMENDMENT TO HOUSE BILL 1198

2            AMENDMENT NO.\_\_\_\_. Amend Senate Bill 1198 by replacing  
3 everything after the enacting clause with the following:

4            "Section 1. Short title. This Act may be cited as the  
5 Newborn Screening Act.

6            Section 5. Rules. The Illinois Department of Public  
7 Health shall promulgate and enforce rules requiring that  
8 every newborn be subjected to tests for phenylketonuria,  
9 hypothyroidism, galactosemia, and other metabolic diseases as  
10 the Department may deem necessary from time to time. In  
11 addition, every newborn whose mother's Human Immunodeficiency  
12 Virus ("HIV") status is unknown must be tested for HIV  
13 antibodies as a routine component of newborn care, subject to  
14 parental or guardian right of refusal. The Department is  
15 empowered to promulgate such additional rules as are  
16 necessary for the administration of this Act, including  
17 mandatory reporting of the results of all tests for these  
18 conditions to the Illinois Department of Public Health. To  
19 protect the confidentiality of test results, all HIV-positive  
20 results shall be reported in accordance with state laws and  
21 rules, including Section 4 of the AIDS Registry Act and 77  
22 Ill. Admin. Code Section 697.210 and 77 Ill. Admin. Code

1 Section 693.30.

2 Section 10. Definitions. In this Act:

3 "Accredited laboratory" means any laboratory that holds a  
4 valid certificate issued under the Clinical Laboratory  
5 Improvement Amendments of 1988, 102 Stat. 2903, 42 U.S.C.  
6 263a, as amended, and that reports its screening results by  
7 using normal pediatric reference ranges.

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

14 "HIV-related test" means a test that detects the presence  
15 of HIV antibodies.

16 "Tandem mass spectrometer" means an analytical instrument  
17 used to detect numerous genetic and metabolic disorders at  
18 one time.

19 Section 15. Powers and duties of Department; tests; fees;  
20 Metabolic Screening and Treatment Fund; penalty. The  
21 Department of Public Health shall administer the provisions  
22 of this Act and shall:

23 (1) Institute and carry on an intensive educational  
24 program among physicians, hospitals, public health  
25 nurses, and the public concerning the diseases  
26 phenylketonuria, hypothyroidism, galactosemia, and other  
27 metabolic diseases. This educational program shall  
28 include information about the nature of the diseases and  
29 examinations for the detection of the diseases in early  
30 infancy so that measures may be taken to prevent the  
31 mental retardation resulting from the diseases.

32 (2) Beginning July 1, 2003, provide all newborns

1 with expanded screening tests for the presence of  
2 genetic, endocrine, or other metabolic disorders,  
3 including phenylketonuria, galactosemia, hypothyroidism,  
4 congenital adrenal hyperplasia, biotinidase deficiency,  
5 and sickling disorders, and other amino acid disorders,  
6 organic acid disorders, fatty acid oxidation disorders,  
7 and other abnormalities detectable through the use of a  
8 tandem mass spectrometer. If, by July 1, 2003, the  
9 Department is unable to provide expanded screening using  
10 the State Laboratory, it shall temporarily provide such  
11 screening through an accredited laboratory selected by  
12 the Department until the Department has the capacity to  
13 provide screening through the State Laboratory. If  
14 expanded screening is provided on a temporary basis  
15 through an accredited laboratory, the Department shall  
16 substitute the fee charged by the accredited laboratory,  
17 plus a 5% surcharge for documentation and handling, for  
18 the fee authorized in item (6) of this Section.

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

22 (4) Supply the necessary treatment product where  
23 practicable for diagnosed cases for as long as medically  
24 indicated when the product is not available through other  
25 State agencies.

26 (5) Arrange for or provide public health nursing,  
27 nutrition and social services, and clinical consultation  
28 as indicated.

29 (6) Require that all specimens collected pursuant  
30 to this Act or the rules promulgated under this Act be  
31 submitted for testing to the nearest Department of Public  
32 Health laboratory designated to perform such tests. The  
33 Department may develop a reasonable fee structure and may  
34 levy fees according to such structure to cover the cost

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

17 Section 20. Powers and duties of Department; HIV tests  
18 and education; penalty.

19 (a) The Department of Public Health shall administer the  
20 provisions of this Act and shall:

21 (1) Institute and carry on an intensive educational  
22 program among physicians, hospitals, public health  
23 nurses, and the public concerning HIV. This educational  
24 program shall include information about the nature of the  
25 disease and the diagnostic test for the detection of the  
26 disease that should be done during pregnancy or for a  
27 newborn within 48 hours of birth (if the HIV status of  
28 the mother is unknown), subject to the right of refusal,  
29 in order that measures may be taken to prevent HIV  
30 infection.

31 (2) Establish a comprehensive program for the  
32 detection of antibodies to the HIV virus. The program  
33 must include instructions on but need not be limited to:

- 1 (i) the requirements of this Act;
- 2 (ii) the benefits of HIV testing for pregnant  
3 women and the newborns whose mother's HIV status is  
4 unknown;
- 5 (iii) the possible interventions to prevent  
6 HIV transmission from a pregnant woman to her fetus  
7 or newborn;
- 8 (iv) the side effects of such interventions;
- 9 (v) the statutory confidentiality provisions  
10 that relate to HIV and acquired immune deficiency  
11 syndrome ("AIDS") testing; and
- 12 (vi) resources available for health care, case  
13 management, counseling, and treatment for people  
14 with HIV and AIDS.

15 (3) Promulgate rules governing the implementation  
16 of the program required under item (2), including the  
17 administration of counseling, testing, disclosure of a  
18 child's test results to the child's mother or other  
19 designated guardian, referral to follow-up care, and  
20 educational activities relating to such testing.

21 If a mother has had an HIV-related test, the person  
22 responsible for testing under this Section may omit an  
23 HIV-related test for the mother's newborn.

24 (b) Any person violating the provisions of this Section  
25 20 is guilty of a petty offense.

26 Section 25. Administration of HIV-related tests to  
27 newborns. The person in charge of each institution that  
28 cares for newborn infants shall cause to have administered an  
29 HIV-related test to every newborn infant in its care whose  
30 mother's HIV status is unknown. Any health care provider who  
31 performs an HIV-related test on a newborn under the  
32 provisions of this Section 25 shall report the results to the  
33 mother or other designated guardian of the newborn within 48

1 hours of the birth of the newborn. The provider shall refer  
2 any newborn who tests positive for HIV to an HIV case manager  
3 and an appropriate health care provider. The provider shall  
4 also give the mother a list of support and health care  
5 services for people with HIV and AIDS. Any person violating  
6 the provisions of this Section 25 is guilty of a petty  
7 offense.

8 Section 30. Objections of parent or guardian.

9 (a) The provisions of this Act related to HIV testing do  
10 not apply to a child if his or her parent or guardian objects  
11 to the HIV testing for any reason. Documentation of such  
12 objection shall be written by the physician or other person  
13 whose duty is to administer such tests under this Act.

14 (b) This Act applies to all screening tests covered by  
15 the Act, except HIV when the parent or guardian of the child  
16 objects thereto on the grounds that such test conflicts with  
17 his or her religious tenets and practices. Documentation of  
18 such objection shall be written by the physician or other  
19 person whose duty is to administer such tests under this Act.

20 Section 75. The State Finance Act is amended by adding  
21 Section 5.595 as follows:

22 (30 ILCS 105/5.595 new)

23 Sec. 5.595. The Metabolic Screening and Treatment Fund.

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