COUNCIL OF THE DISTRICT OF COLUMBIA NOTICE

D. C. LAW 3-65

"District of Columbia Newborn Screening Requirement Act of 1979"

Pursuant to Section 412 of the District of Columbia Self-Government and Governmental Reorganization Act, P. L. 93-198, "the Act", the Council of the District of Columbia adopted Bill No. 3-126, on first and second readings, January 22, 1980 and February 5, 1980 respectively. Following the signature of the Mayor on March 4, 1980, this legislation was assigned Act No. 3-163, published in the March 14, 1980, edition of the D.C. Register, (Vol. 27 page 1087) and transmitted to Congress on March 7, 1980 for a 30-day review, in accordance with Section 602 (c)(1) of the Act.

The Council of the District of Columbia hereby gives notice that the 30-day Congressional Review Period has expired, and, therefore, cites this enactment as D.C. Law 3-65 effective April 29, 1980.

ARRINGTON DIXON
Chairman of the Council

Dates Counted During the 30-day Congressional Review Period:

March 7, 10, 11, 12, 13, 14, 17, 18, 19, 20, 21, 24, 25 26, 27, 28, 31

April 1, 2, 3, 15, 16, 17, 18, 21, 22, 23, 24, 25, 28

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AN ACT

D.C. ACT3 - 16 3

IN THE COUNCIL OF THE DISTRICT OF COLUMBIA

MAR 04 1980

To require certain screening tests to be administered to all infants born in hospitals in the District of Columbia.

BE IT ENACTED BY THE COUNCIL OF THE DISTRICT OF COLUMBIA.

That this act may be cited as the "District of Columbia

Newborn Screening Requirement Act of 1979".

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Sec.	2.	Purpose	D.C. Code,
			sec. 6-211

It is the purpose of this legislation to provide for the early identification of certain metabolic disorders in newborns in the District of Columbia so that referral and treatment, where appropriate, may be provided.

Sec. 3. <u>Definitions</u>.

D.C. Code, sec. 6-212

Unless otherwise specified the following definitions

apply:

- (a) The term "metabolic disorder" means a disorder which results in a defect in the function of a specific en Tyme or protein.
- (b) The term "hypothyroidism" means those clinical conditions which result from abnormally low circulating levels of thyroid normone.
- (c) The term "newborn" means any infant born in the District who is under four (4) weeks of age.
- (d) The term "phenylketonuria", hereinafter referred to as "PKU", means the metabolic disease of the newborn in which metabolites of phenylalanine appear in urine.
- Sec. 4. Testing and Follow-up for Hypothyroidism. PKU.

 and other Metabolic Disorders of the Newborn.

 D.C. Code,
 sec. 6-213
- (a) All hospitals in the District of Columbia shall administer to all newborns a blood test to screen for Hypothyroidism, and PKU. Testing for other metabolic disorders may also be required if the Mayor so specifies by

regulation, with the advice of the District of Columbia Committee on Metabolic Disorders.

- (b) Each test shall be forwarded to a single laboratory designated by the Mayor. The designated laboratory must be one which is currently certified by the College of American Pathologists and regularly participates in the appropriate quality control program for such testing by the College or is currently certified by the United States Center for Disease Control and regularly participates in the appropriate quality control program for such testing by the Center or has a federal license under the Clinical Latoratories Improvement Act of 1967, approved December 5, 19"7 (81 State 536; 42 U.S.C. 263a), which permits the la oratory to solicit and accept in interstate commerca human specimens for the purpose of performing clinical lacoratory examinations, for the purpose of detecting metabolic disorders.
- (c) All test results shall be returned to the hospital where the baby was born. In addition, all positive test results shall be returned to the parent and to a physician designated by the District of Columbia government. The physician shall assist a parent and her physician in securing appropriate follow-up testing and treatment when indicated.

Sec. 5. <u>Principles Governing Newborn Screening</u>.

The Mayor shall insure that:

D.C. Code, sec. 6-214

- (a) Carriers of metabolic disorders should not be stigmatized and should not be discriminated against by any person within the District of Columbia;
- (b) District of Columbia policy regarding metabolic disorders should be made with full public knowledge, in light of expert opinion, and should be periodically reviewed to consider changing medical knowledge and ensure full oullic protection;
- (c) Participation of persons in metabolic disorder programs in the District of Columbia should be wholly vo untary, and that all information obtained from persons involved in metabolic disorder programs in the District of Co umbia should be held strictly confidential, except as provided for in paragraph (4); and that in carrying out the mandate of this subsection the Mayor shall further insure that:
- (1) No test be performed on any newborn over the objections of his or her parent and that no test be performed unless such parent is fully informed of the purpose of testing for metabolic disorders, and is given a reasonable opportunity to object to such testing;

- (2) No program requires mandatory participation.

 or restriction of childbearing. or be a prerequisite to eliqibility for, or receipt of any other service or assistance from or to participation in any other program;
- disorders be protected from undue physical or mental harm. be informed of the nature of risks involved in participation in such a program or project. be informed of the nature and cost of available therapies or maintenance programs for those affected by metabolic disorders, and be informed of the possible benefits and risks of such therapies and programs; and
- (4) Except for statistical data compiled without reference to the identity of any individual, all information obtained from any individual, or from specimens from any newborn shall be held confidential and be considered a confidential medical record except for such information as the parent consents to be released. The parent must be informed of the scope of the information requested to be refeased and the purpose for releasing such information.

Sec. 6. Committee on Metabolic Disorders Created.

D.C. Code, sec. 6-215

(a) The Committee on Metabolic Disorders. (hereinafter referred to as the "Committee"). shall be composed of nine

- (9) members. The members shall be appointed by the Mayor.

 Each member shall serve a term of three (3) years or until
 his or her successor is appointed and qualified, except that
 in the initial appointments three (3) members shall serve
 for one (1) year, three (3) members for two (2) years and
 three (3) members for three (3) years. No member shall be
 appointed to more than three (3) consecutive three (3) year
 terms. The members of the Committee shall serve without
 compensation.
- (b) Four (4) members of the Committee shall be consumer members. A consumer is defined as a person who is not a health professional, nor involved in the administration or ownership of any health care institution or health insurance organization, nor the spouse of a health professional, administrator, or owner. Two (2) of the consumer members shall be appointed from a list of five (5) names submitted to the Mayor by the District of Columbia Association for Refarded Citizens, Inc. Five (5) of the members of the Committee shall be non-consumers. Four (4) of the non-consumer members shall be licensed physicians knowledgeable in the diagnosis and treatment of metabolic disorders. At least one (1) of the physicians shall be either a geneticist or an endocrinologist. The Director of the Department of

Human Resources, or his or her designate, shall serve as an ex-officio non-voting member of the Committee.

- reason other than the normal expiration of a term of office, a member shall be promptly appointed, to complete the unexpired term of the resigning member. The replacement member shall be selected in the same manner as outlined in sufsection (b).
- (d) The Mayor shall appoint a chairperson from among the members of the Committee to serve from the time of the Committee formation until December 31st of the year of the formation of the Committee. Thereafter the Mayor, each year, shall appoint a chairperson to serve a one (1) year term to run from January 1st to December 31st of each year.
- (e) The full Committee shall meat at least twice each vear. Business may be conducted if a majority of the members are present.
 - Sec. 7. <u>Duties of the Committee on Metabolic Disorders</u>.

 The Committee shall:
- D.C. Code, sec. 6-216
- (a) Gather and disseminate information to further the public's understanding of metabolic disorders:
- (b) Consult the public, especially committees and groups of persons particularly affected by metabolic disorder programs;

- (c) Make available to the public information on the operation of all programs on metabolic disorders within the District of Columbia, except for confidential information;
- (d) Reevaluate on a continuous basis the need for and efficacy of administering the blood screening test for hypothyroidism, and PKU to all newborns in the District of Cofumbia;
- (e) Recommend to the Mayor any additional screening tests for metabolic disorders that should be added to those required under section 4 (a);
- (f) Recommend to the Mayor any screening tests for me^Cabolic disorders required under section (4) (a) that should be deleted;
- (q) Consider the incidence of each metabolic disorder and the cost of detection and management of each metabolic disorder, and where appropriate consult. District of Columbia and national experts concerning the medical, osychological, ethical, social and economic effects of programs for the detection and management of metabolic disorders;
- (h) Keep the Mayor informed as to new and improved techniques for screening and testing newborns for metabolic disorders; and

(i) Recommend to the Mayor the single laboratory where the screening tests for metabolic disorders will be performed.

Sec. 8. Annual Report to the Mayor and the Council.

D.C. Code, sec. 6-217

The Committee shall submit to the Mayor and the Council on January 1st of each year a report summarizing the activities of the Committee, and containing any recommendations to the Mayor and the Council which the Committee deems necessary regarding problems of metabolic disorders.

Sec. 9. Laboratory Costs.

D.C. Code, sec. 6-218

Laboratory costs of the screening tests shall be borne by the District of Columbia government. No hospital may charge for the test.

Sec. 10. Payment Authorization.

D.C. Code, sec. 6-219

There is hereby authorized to be appropriated out of the general revenues of the District of Columbia government sufficient funds to carry out the requirements of this actincluding treatment when the parent is unable to pay for it.

Sec. 11. Effective Date.

This act shall take effect on October 1, 1980, after a thirty (30) day period of Congressional review following approval by the Mayor (or in the event of veto by the Mayor, action by the Council of the District of Columbia to

override the veto) as provided in section 602(c)(1) of the District of Columbia Self-Government and Governmental Reorganization Act, approved December 24, 1973 (87 Stat. 817; D.C. Code, sec. 1-147(c)(1)).

Chairman Pulan

Council of the District of Columbia

1277

Mayor District of Columbia

APPROVED: March 4, 1980

COUNCIL OF THE DISTRICT OF COLUMBIA RECORD OF CHICLAL COUNCIL ACTION

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