

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
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

D.C. LAW 3-65
EFFECTIVE DATE APR 29 1980

AN ACT

D.C. ACT 3-163

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. <u>Purpose.</u>	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. Definitions.

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 enzyme or protein.

(b) The term "hypothyroidism" means those clinical conditions which result from abnormally low circulating levels of thyroid hormone.

(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 Laboratories Improvement Act of 1967, approved December 5, 1967 (81 Stat. 536; 42 U.S.C. 263a), which permits the laboratory to solicit and accept in interstate commerce human specimens for the purpose of performing clinical laboratory 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. Principles Governing Newborn Screening.

D.C. Code,
sec. 6-214

The Mayor shall insure that:

(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 public protection;

(c) Participation of persons in metabolic disorder programs in the District of Columbia should be wholly voluntary, and that all information obtained from persons involved in metabolic disorder programs in the District of Columbia 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 eligibility for, or receipt of any other service or assistance from or to participation in any other program;

(3) All participants in programs on metabolic 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 released and the purpose for releasing such information, prior to the release of any confidential 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 Retarded 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.

(c) When a vacancy on the Committee occurs for any 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 subsection (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 meet at least twice each year. Business may be conducted if a majority of the members are present.

Sec. 7. Duties of the Committee on Metabolic Disorders.

D.C. Code,
sec. 6-216

The Committee shall:

(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 Columbia;

(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 metabolic disorders required under section (4) (a) that should be deleted;

(g) 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, psychological, 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 act, including 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

COUNCIL OF THE DISTRICT OF COLUMBIA

RECORD OF OFFICIAL COUNCIL ACTION

DOCKET NO: Bill 3-126

ACTION: To Adopt (1-22-80) First Reading

VOICE VOTE: Unanimous

Absent: Spaulding and Wilson

ROLL CALL VOTE:

COUNCIL MEMBER	AYE	NAY	N.V.	A.B.	COUNCIL MEMBER	AYE	NAY	N.V.	A.B.	COUNCIL MEMBER	AYE	NAY	N.V.	A.B.
DIXON					KANE					SHACKLETON				
WINTER					MASON					SPAULDING				
CLARKE					MOORE					WILSON				
HARDY					RAY									
TARVIS					ROLARK									

K-Indicates Vote A. Absences N.V. - Not Voting

CERTIFICATION OF RECORD

[Signature]
Secretary to the Council

ACTION: To Adopt (2-5-80) Final Reading

VOICE VOTE: Unanimous

Absent: Clarke

ROLL CALL VOTE:

COUNCIL MEMBER	AYE	NAY	N.V.	A.B.	COUNCIL MEMBER	AYE	NAY	N.V.	A.B.	COUNCIL MEMBER	AYE	NAY	N.V.	A.B.
DIXON					KANE					SHACKLETON				
WINTER					MASON					SPAULDING				
CLARKE					MOORE					WILSON				
HARDY					RAY									
TARVIS					ROLARK									

K-Indicates Vote A. Absences N.V. - Not Voting

CERTIFICATION OF RECORD

[Signature]
Secretary to the Council

ACTION: _____

VOICE VOTE: _____

Absent: _____

ROLL CALL VOTE:

COUNCIL MEMBER	AYE	NAY	N.V.	A.B.	COUNCIL MEMBER	AYE	NAY	N.V.	A.B.	COUNCIL MEMBER	AYE	NAY	N.V.	A.B.
DIXON					KANE					SHACKLETON				
WINTER					MASON					SPAULDING				
CLARKE					MOORE					WILSON				
HARDY					RAY									
TARVIS					ROLARK									

K-Indicates Vote A. Absences N.V. - Not Voting

CERTIFICATION OF RECORD

Secretary to the Council