

SB0242/503022/1

BY: Health and Government Operations Committee

AMENDMENTS TO SENATE BILL 242
(Third Reading File Bill)

AMENDMENT NO. 1

On page 1, in line 5, strike “core”; in line 7, after “Panel” insert “, subject to the approval of the State Advisory Council on Hereditary and Congenital Disorders and the Secretary of Health; establishing certain requirements related to the approval or disapproval of the inclusion of a condition and the implementation of testing for a condition approved for inclusion in the system for newborn screening”; and in line 10, after “Section” insert “13-101 and”.

AMENDMENT NO. 2

On page 1, after line 15, insert:

“13-101.

(a) In this subtitle the following words have the meanings indicated.

(B) “ADVISORY COUNCIL” MEANS THE STATE ADVISORY COUNCIL ON HEREDITARY AND CONGENITAL DISORDERS.

[(b)] (C) “Commission” means the State Commission on Hereditary and Congenital Disorders.

[(c)] (D) (1) “Congenital disorder” means a significant structural or functional abnormality of the body that is present at birth.

(2) “Congenital disorder” does not include a condition that results from:

(i) An intrauterine infection; or

(ii) A birth injury.

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~~[(d)]~~ **(E)** “Hereditary disorder” means any disorder that:

(1) Is transmitted through the genetic material deoxyribonucleic acid (DNA); or

(2) Arises through the improper processing of the information in the genetic material.”.

On page 3, in line 6, strike “**NOTWITHSTANDING**” and substitute “**SUBJECT TO THE APPROVAL OF THE SECRETARY AND THE ADVISORY COUNCIL UNDER PARAGRAPH (2) OF THIS SUBSECTION AND NOTWITHSTANDING**”; strike beginning with “**DEPARTMENT**” in line 10 down through “**PANEL**” in line 12 and substitute “**SECRETARY AND THE ADVISORY COUNCIL SHALL DETERMINE WHETHER TO APPROVE THE INCLUSION OF A CONDITION IN THE SYSTEM FOR NEWBORN SCREENING**”; in lines 12 and 13, strike “**2 YEARS**” and substitute “**1 YEAR**”; in line 13, strike “**PANEL**” and substitute “**RECOMMENDED UNIFORM SCREENING PANEL**”; after line 13, insert:

“(III) IF THE SECRETARY OR ADVISORY COUNCIL DOES NOT APPROVE THE INCLUSION OF A CORE CONDITION IN THE SYSTEM FOR NEWBORN SCREENING UNDER SUBPARAGRAPH (I) OF THIS PARAGRAPH:

1. WITHIN 1 YEAR AFTER THE ADDITION OF THE CONDITION TO THE RECOMMENDED UNIFORM SCREENING PANEL, THE DEPARTMENT SHALL PUBLICLY POST AND SUBMIT TO THE GENERAL ASSEMBLY, IN ACCORDANCE WITH § 2-1257 OF THE STATE GOVERNMENT ARTICLE, A REPORT THAT INCLUDES, AS APPLICABLE, THE SECRETARY’S JUSTIFICATION FOR NOT APPROVING THE INCLUSION AND THE FINAL VOTE OF THE ADVISORY COUNCIL REGARDING THE INCLUSION OF THE CONDITION; AND

2. EACH YEAR AFTER THE INITIAL DISAPPROVAL, THE ADVISORY COUNCIL SHALL:

A. REVIEW THE MEDICAL LITERATURE PUBLISHED ON THE CONDITION SINCE THE INITIAL EVALUATION AND DETERMINE WHETHER SUBSTANTIVE UPDATES HAVE OCCURRED THAT WOULD MERIT FORMAL REEVALUATION OF THE INCLUSION OF THE CONDITION; AND

B. IF THE ADVISORY COUNCIL UPHOLDS ITS DISAPPROVAL OF THE CONDITION, PUBLICLY PUBLISH AND SUBMIT TO THE GENERAL ASSEMBLY, IN ACCORDANCE WITH § 2-1257 OF THE STATE GOVERNMENT ARTICLE, A REPORT ON THE REASON FOR THE DISAPPROVAL.”;

after line 16, insert:

“(F) IF THE SECRETARY AND THE ADVISORY COUNCIL APPROVE THE INCLUSION OF A CONDITION IN THE SYSTEM FOR THE NEWBORN SCREENING UNDER SUBSECTION (E) OF THIS SECTION, THE DEPARTMENT SHALL IMPLEMENT TESTING FOR THE CONDITION WITHIN 1 YEAR AFTER THE DATE OF THE APPROVAL.”;

and in line 17, strike “(f)” and substitute “**(G)**”.