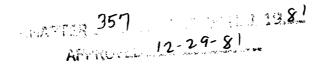
# 26:2-110 to 26:2-112

#### LEGISLATIVE HISTORY CHECKLIST

NJSA 26:2-11026:2-112		Newborn require			emical dis	sorder
LAWS 1981	<b>300</b>	CHAPTER		357		-
Bill No. S78	_					
Sponsor(s) Scardino						-
Date Introduced Pre	e-filed					
Committee: Assembly In	nstitutions, Heal	lth & Wel	fare	and the second s		
Senate Ir	nstitutions, Hea	lth & Wel	fare			
Amended during passage	Yes		<b>N</b> ĕ		nts durin by aster	
Date of Passage: Assembly	Dec. 7, 198	1	•	d ciro coa	<b>-</b>	
Senate_	May 19, 198	0				
Date of approval	Dec. 29, 19	81	<u>.</u>			
Following statements are a	ittached if avail	lable:				
Sponser statement	Yes		Nox			
Committee Statement: Asse	embly Yesk	,	No			
Sena	ite Yes		Nox 1	l-16-81 &	5-1-80 8	1-24-80
Fiscal Note	Yes		Nox			
Veto Message	Yesx		No			
Message on signing	Yes	:	Ио			
Following were printed:						
Reports	Y <del>¢</del> ⊗x	;	No			
Hearings	Yesx	ì	No			



# [SECOND OFFICIAL COPY REPRINT] SENATE, No. 78

## STATE OF NEW JERSEY

PRE-FILED FOR INTRODUCTION IN THE 1980 SESSION

#### By Senator SCARDINO

An Acr to amend the title of "An act providing for the testing of newborn children for purposes of the early detection of hypothyroidism," approved January 10, 1978 (P. L. 1977, c. 321), so that the same shall read "An act providing for the testing of newborn children for purposes of the early detection of \*\* hypothyroidism, galactosemia, maple sugar urine disease and homocystinuria," and to amend the body of said act \*\* \*\*" biochemical disorders," to amend and supplement the body of said act, and to repeal P. L. 1964, c. 268 (C. 26:2-84 et seq.)\*\*.

- 1 Be it enacted by the Senate and General Assembly of the State
- 2 of New Jersey:
- 1. The title of P. L. 1977, c. 321 is amended to read as follows:
- 2 An act providing for the testing of newborn children for purposes
- 3 of the early detection of \*\* Thypothyroidism, galactosemia, maple
- 4 sugar urine disease, and homocystinuria 1 \*\* \*\* biochemical dis-
- 5 orders\*\*.
- 2. Section 1 of P. L. 1977, c. 321 (C. 26:2-110) is amended to read
- 2 as follows:
- 3 1. It is hereby declared to be the public policy of this State that
- 4 in the interests of public health every \*\* newborn infant should be
- 5 given a test approved by the State Department of Health for the
- 6 detection of hypothyroidism, galactosemia, maple sugar urine dis-
- 7 ease and homocystinuria in order to prevent mental retardation
- 8 resulting from [this disease] these diseases. [No] All newborn
- 9 infants shall be so tested, except that no such test shall be made on
- 10 any newborn infant if the parents of said child object thereto on
- 11 the grounds that such a test would conflict with their religious
- 12 tenets or practices.]\*\* \*\*effort should be made to detect in newborn
- 13 infants, hypothyroidism, galactosemia, phenylketonuria, and other

EXPLANATION—Matter enclosed in bold-faced brackets Ithus in the above bill is not enacted and is intended to be omitted in the law,

14 preventable biochemical disorders which may cause mental retarda-

2

- 15 tion or other permanent disabilities.\*\*
- 3. Section 2 of P. L. 1977, c. 321 (C: 26:2-111) is amended to
- 2 read as follows:
- 3 2. \*\* The State Department of Health shall institute and carry
- 4 on such laboratory services as are deemed necessary by the Public
- 5 Health Council and \*\* \*\* All newborn infants shall be tested for
- 6 hypothyroidism, galactosemia and phenylketonuria. The Commis-
- 7 sioner of Health shall issue regulations to assure that newborns
- 8 are so tested in a manner approved by the commissioner. The State
- 9 Department of Health may charge a reasonable fee for the tests
- 10 performed pursuant to this act. The amount of the fee and the pro-
- 11 cedures for collecting the fee shall be determined by the commis-
- 12 sioner.
- 13 The commissioner may also require testing of newborn infants
- 14 for other preventable biochemical disorders if reliable and efficient
- 15 testing techniques are available. If the commissioner determines
- 16 that an additional test shall be required, 90 days prior to requiring
- 17 the test he shall advise the President of the Senate, Speaker of the
- 18 General Assembly and chairmen of the standing reference commit-
- 19 tees on Revenue, Finance and Appropriations and Institutions,
- 20 Health and Welfare of his determination.
- 21 The commissioner shall provide a program of reviewing and
- 22 following up on positive cases in order that measures may be taken
- 23 to prevent mental retardation or other permanent disabilities.
- 24 Information on newborn infants and their families compiled pur-
- 25 suant to this section may be used by the department and agencies
- 26 designated by the commissioner for the purposes of carrying out
- 27 this act, but otherwise the information shall be confidential and not
- 28 divulged or made public so as to disclose the identity of any person
- $29 \quad to \ which \ it \ relates, \ except \ as \ provided \ by \ law. \ The \ department \ shall$
- 30 conduct\*\* an intensive educational and training program among
- 31 physicians, hospitals, public health nurses and the public concern-
- 32 ing \*\* [the [disease] diseases of hypothyroidism, galactosemia,
- 33 maple sugar urine disease and homocystinuria \*\* \*\* those biochem-
- 34 ical disorders\*\*. This program shall include information concering

the nature of the [disease] \*\* [diseases] \*\* \*\* disorders \*\* and test-

- 36 ing for the detection of [this disease] these \*\* [diseases in infancy
- 37 in order that measures may be taken to prevent mental retardation
- 38 resulting from [this disease] these diseases.]\*\* \*\*disorders.\*\*
- 39 \*\* The State Commissioner of Health shall make rules governing
- 40 the submission to the State Laboratory of specimens for testing
- 41 for hypothyroidism, galactosemia, maple sugar urine disease, and
- 42 homocystinuria.

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43
      The commissioner shall provide a program of reviewing and
    following up on positive cases in order that measures may be taken
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    to prevent mental retardation resulting from the [disease]
45
    diseases. 1**
46
      **The provisions of this section shall not apply if the parents of
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    a newborn infant object to the testing on the grounds that it would
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    conflict with their religious tenets or practices.**
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      *** ** 4. The State Commissioner of Health shall report to the
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    Governor and the chairmen of the Senate and Assembly Institu-
    tions, Health and Welfare committees 90 days following enactment
3
    of this act about the progress of establishing procedures for test-
    ing for maple sugar urine disease and homocystinuria.**
      **4. The commissioner is authorized to enter into agreements
 1
    with the Federal Government and public health agencies in other
 ^{2}
    states to achieve greater effectiveness or efficiency in carrying out
 3
    the provisions of this act.
 1
      5. P. L. 1964, c. 268 (C. 26:2-84 et seq.) is repealed.**
      *[4.]* **[*5.*]** **6.** This act shall take effect 90 days fol-
 1
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lowing enactment \*\* \* \* except that the requirement concerning test-

ing for maple sugar urine disease and homocystinuria shall take

effect 6 months following enactment\*]\*\*.

 $^2$ 

- 7 public concerning the [disease] diseases of hypothyroidism, galac-
- 8 tosemia, maple sugar urine disease and homocystinuria. This pro-
- 9 gram shall include information concerning the nature of the [dis-
- 10 ease diseases and testing for the detection of this disease these
- 11 diseases in infancy in order that measures may be taken to prevent
- 12 mental retardation resulting from [this disease] these diseases.
- 13 The State Commissioner of Health shall make rules governing the
- 14 submission to the State Laboratory of specimens for testing for
- 15 hypothyroidism, galactosemia, maple sugar urine disease, and
- 16 homocystinuria.
- 17 The commissioner shall provide a program of reviewing and
- 18 following up on positive cases in order that measures may be taken
- 19 to prevent mental retardation resulting from the [disease]
- 20 diseases.
- 4. This act shall take effect 90 days following enactment.

#### STATEMENT

Current law (P. L. 1977, c. 321) declares it to be State policy that every newborn infant be tested for hypothyroidism. This bill would make it mandatory that testing be conducted for hypothyroidism as well as galactosemia, maple sugar urine disease, and homocystinuria. These are all metabolic disorders which can seriously damage the physical and mental health of children and can lead to severe retardation. The State has the responsibility to take every possible step to safeguard and protect the health of its children and mandatory testing is one such method.

578 (1980)

# SENATE INSTITUTIONS, HEALTH AND WELFARE COMMITTEE STATEMENT TO SENATE STATEMENT TO

## STATE OF NEW JERSEY

DATED: NOVEMBER 16, 1981

Currently the statutes provide that it is State policy that all newborn infants should be tested for phenylketonuria (PKU) and hypothyroidism. This bill amends present law so that it is mandatory that all newborn infants be tested for PKU, hypothyroidism and galactosemia.

The bill also authorizes the Commissioner of Health to:

- (1) Set and charge a fee for testing done pursuant to the requirements of this act.
- (2) Require testing of newborns for other biochemical disorders if effective testing methods are available. If a test for another disorder is to be required, the Legislature shall receive 90 days advance notice of such test.
- (3) Enter into agreements with the Federal Government and public health agencies in other states to achieve greater effectiveness in carrying out the provisions of this act.
- (4) Compile certain information on newborns to be used in carrying out the purposes of this bill. The information may be used by the department and certain agencies, but otherwise shall remain confidential.

Through genetic screening and testing programs, newborn infants with inherited genetic defects and other biochemical disorders can be detected. If left untreated, these disorders almost invariably lead to mental retardation. If detected early and therapy is begun, there is usually no resultant brain damage.

The Assembly Institutions, Health and Welfare Committee supports the concept of this bill and released it without amendment.

## SENATE INSTITUTIONS, HEALTH AND WELFARE COMMITTEE

STATEMENT TO

#### SENATE, No. 78

## STATE OF NEW JERSEY

DATED: MAY 1, 1980

This bill amends P. L. 1977, c. 321 (C. 26:2-110 et seq.) to require that all newborn infants be tested for hypothyroidism, phenylketonuria (PKU) and galactosemia. These are biochemical disorders which can seriously damage the physical and mental health of newborns and lead to severe mental retardation. Current law declares it to be State policy that every newborn should be tested for hypothyroidism (C. 26:2-110 et seq.) and PKU (C. 26:2-84 et seq.). This bill adds the disorder of galactosemia and makes the testing for each of these disorders mandatory.

The bill authorizes the Commissioner of Health to: set and charge a fee for any testing done pursuant to this act; require testing for other disorders if reliable and efficient testing techniques are available, and advise the Legislature, 90 days in advance, if another test shall be required; and, enter into agreements with the Federal Government and public health agencies in other states to achieve greater effectiveness and efficiency in carrying out this act. The bill also provides that the information compiled on newborns and their families shall be confidential and only may be used by the Department of Health and agencies designated by the commissioner.

The committee amended this bill to add the provisions described above and to delete the requirement for testing for maple sugar urine disease and homocystinuria. The two disorders were deleted because the incidence of these disorders is very low and current testing techniques are not reliable or efficient. The bill does not provide an appropriation for the additional testing that is mandated, however, if additional funds are needed by the department to implement this act, committee amendments provide that the department may charge a fee for the testing. The commissioner is authorized to set the fee and to determine the most efficient way for collecting this fee.

## SENATE INSTITUTIONS, HEALTH AND WELFARE COMMITTEE

STATEMENT TO

#### SENATE, No. 78

with Senate committee amendments

### STATE OF NEW JERSEY

DATED: JANUARY 24, 1980

This bill requires the Department of Health to test newborns for hypothyroidism, galactosemia, maple sugar urine disease and homocystinuria. These are all metabolic disorders which can seriously damage the physical and mental health of children and can lead to severe mental retardation.

Current law declares it to be State policy that every newborn be tested for hypothyroidism. This bill makes such testing mandatory and also requires testing for three other metabolic disorders.

The committee amended the bill to change the effective date for testing for maple sugar urine disease and homocystinuria from 90 days to 6 months after the date of enactment. This change was made in order to allow the Department of Health time to acquire the necessary equipment and develop procedures for this specialized kind of testing. The committee also amended the bill to require the Commissioner of Health, within 90 days of enactment, to report to the Governor and Legislature on the progress of establishing procedures for testing for maple sugar urine disease and homocystinuria. It is the committee's intent that the Department of Health will establish regulations which mandate who is responsible for ensuring that the testing is done on each newborn.

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FISCAL NOTE TO SENATE, No. 78

### STATE OF NEW JERSEY

DATED: SEPTEMBER 29, 1980

The Second Official Copy Reprint of Senate Bill No. 78 of 1980 provides for the testing of newborn children for the purposes of the early detection of biochemical disorders.

The Department of Health estimates that enactment of this legislation would increase the revenues of the State by \$92,854.00 in fiscal 1980-81, \$136,437.00 in fiscal 1981-82 and \$121,689.00 in fiscal 1982-83.

The above estimates are based on screening 90,000 newborns.

The Office of Legislative Services points out that although no funds are specifically appropriated for this purpose, a fee structure is permitted. The department is setting up a revolving fund which more than pays for the program.

In compliance with written request received, there is hereby submitted a fiscal estimate for the above bill, pursuant to P. L. 1962, c. 27.