

Reprinted 3/10/83

11 ... Resources 2/7
SENATE FILE 188 Do Pass 3/2/83 (p.591)

Human Resources
Gentleman, Chair
Horn
Mann

SENATE FILE 188

BY SCHWENGELS and GENTLEMAN

Finance 3/3/83 Do Pass 3/4 (p.639)
FILED FEB 3 1983

Passed Senate, Date 3-7-83 (p.646) Passed House, Date 4-8-83 (p.1122)
Vote: Ayes 46 Nays 1 Vote: Ayes 90 Nays 0
Approved April 21, 1983 (p.1365)

A BILL FOR

1 An Act relating to the birth defects institute within the
2 state department of health.

3 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

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S.F. 1

SENATE FILE 188

S-3162

1 Amend Senate File 188 as follows:
2 1. Page 1, line 23, by inserting after the word
3 "disease." the words "The birth defects institute
4 shall assume responsibility for development and im-
5 plementation of screening and educational programs for
6 sickle cell anemia and other genetic blood disorders."

S-3162 FILED
MARCH 3, 1983

BY TOM MANN, JR.
JULIA GENTLEMAN

Adopted 3/7/83 (p.646)

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1 Section 1. Section 136A.1, Code 1983, is amended to read
2 as follows:

3 136A.1 PURPOSE. In order to provide for the protection
4 and promotion of the health of the inhabitants of the state,
5 the state department of health shall ~~have the responsibility~~
6 ~~for the development~~ develop and ~~administration of~~ administer
7 the state's policy with respect to the conduct of scientific
8 investigations and research concerning the causes, prevention,
9 treatment and cure of birth defects. The department shall
10 initiate, conduct, and supervise screening programs to discover
11 genetic birth defects and related diseases and to prevent
12 or treat the defects or diseases.

13 Sec. 2. Section 136A.2, Code 1983, is amended to read
14 as follows:

15 136A.2 ESTABLISHMENT OF BIRTH DEFECTS INSTITUTE. There
16 is established within the state department of health a birth
17 defects institute ~~for the purposes of initiating~~ to initiate
18 and ~~conducting~~ conduct investigations of the causes, mortality,
19 methods of treatment, prevention and cure of birth defects
20 and related diseases and to develop and administer genetic
21 and metabolic screening programs and other related activities
22 where the programs will aid in the prevention or treatment
23 of a particular genetic or metabolic defect or disease.

24 Sec. 3. NEW SECTION. 136A.2A GENETIC AND METABOLIC
25 SCREENING DEFINED. Genetic and metabolic screening means
26 the search through testing for persons with genetic and
27 metabolic diseases so that early treatment or counseling can
28 lead to the amelioration or avoidance of the adverse
29 consequences of the diseases.

30 Sec. 4. Section 136A.3, Code 1983, is amended to read
31 as follows:

32 136A.3 ACTIVITIES OF THE INSTITUTE. The birth defects
33 institute may:

34 1. Conduct scientific investigations and surveys of the
35 causes, mortality, methods of treatment, prevention and cure

1 of birth defects.

2 2. Publish the results of ~~such~~ the investigations and
3 surveys for the benefit of the public health and collate ~~such~~
4 the publications for distribution to scientific organizations
5 and qualified scientists and physicians.

6 3. Develop and administer genetic and metabolic screening
7 programs to detect and prevent or treat birth defects, the
8 programs to be conducted throughout the state.

9 4. Develop specifications for and designate a central
10 laboratory in which tests required pursuant to the screening
11 programs required in subsection 3 will be performed, taking
12 into account the test costs to the financially responsible
13 private parties and to the state.

14 3 5. Implement programs of professional education and
15 training of medical students, physicians, nurses, scientists
16 and technicians in the causes, methods of treatment, prevention
17 and cure of birth defects.

18 6. Implement public educational programs to inform persons
19 of the importance of genetic screening and of the various
20 opportunities available.

21 4 7. Conduct and support clinical counseling services
22 in medical facilities.

23 Sec. 5. NEW SECTION. 136A.4 RULES, REGULATIONS, AND
24 STANDARDS. The birth defects institute, with assistance pro-
25 vided by the state department of health, shall adopt rules
26 pursuant to chapter 17A to implement this chapter.

27 Sec. 6. NEW SECTION. 136A.5 CENTRAL REGISTRY--
28 CONFIDENTIALITY. The birth defects institute may maintain
29 a central registry to collect and store report data to
30 facilitate the compiling of statistical information on the
31 causes, treatment, prevention, and cure of genetic disorders
32 and birth defects. Identifying information shall remain
33 confidential pursuant to section 68A.7, subsection 2.

34 Sec. 7. NEW SECTION. 136A.6 COOPERATION OF OTHER
35 AGENCIES. All state, district, county, and city health or

1 welfare agencies shall cooperate and participate in the
2 implementation of this chapter.

3 Sec. 8. Section 135.31 and chapter 141, Code 1983, are
4 repealed.

5 EXPLANATION

6 This bill expands the responsibility of the birth defects
7 institute within the state department of health. The institute
8 shall develop and administer genetic and metabolic screening
9 programs for genetic and metabolic defects or diseases.

10 The bill permits the birth defects institute to designate
11 a central laboratory to perform the necessary testing and
12 to adopt rules to implement the chapter relating to the birth
13 defects institute. The bill permits the birth defects
14 institute to maintain a confidential central registry for
15 the compilation of data.

16 The bill repeals the section requiring testing for
17 phenylketonuria and the chapter relating to the testing for
18 sickle cell anemia but permits the birth defects institute
19 to continue the testing for phenylketonuria and sickle cell
20 anemia.

21 This bill takes effect July 1 following enactment.

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SENATE FILE 188

BY SCHWENGELS and GENTLEMAN

Substituted for H. F. 191

(AS AMENDED AND PASSED BY THE SENATE MARCH 7, 1983)

Passed Senate, Date 3-7-83 (p. 646) Passed House, Date 4-8-83 (p. 1129)

Vote: Ayes 46 Nays 1 Vote: Ayes 90 Nays 0

Approved April 21, 1983 (p. 1365)

A BILL FOR

1 An Act relating to the birth defects institute within the
2 state department of health.

3 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

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————— = New Language
by the Senate

1 Section 1. Section 136A.1, Code 1983, is amended to read
2 as follows:

3 136A.1 PURPOSE. In order to provide for the protection
4 and promotion of the health of the inhabitants of the state,
5 the state department of health shall ~~have-the-responsibility~~
6 ~~for-the-development~~ develop and ~~administration-of~~ administer
7 the state's policy with respect to the conduct of scientific
8 investigations and research concerning the causes, prevention,
9 treatment and cure of birth defects. The department shall
10 initiate, conduct, and supervise screening programs to discover
11 genetic birth defects and related diseases and to prevent
12 or treat the defects or diseases.

13 Sec. 2. Section 136A.2, Code 1983, is amended to read
14 as follows:

15 136A.2 ESTABLISHMENT OF BIRTH DEFECTS INSTITUTE. There
16 is established within the state department of health a birth
17 defects institute ~~for-the-purposes-of-initiating~~ to initiate
18 ~~and conducting~~ conduct investigations of the causes, mortality,
19 methods of treatment, prevention and cure of birth defects
20 and related diseases and to develop and administer genetic
21 and metabolic screening programs and other related activities
22 where the programs will aid in the prevention or treatment
23 of a particular genetic or metabolic defect or disease. The
24 birth defects institute shall assume responsibility for
25 development and implementation of screening and educational
26 programs for sickle cell anemia and other genetic blood
27 disorders.

28 Sec. 3. NEW SECTION. 136A.2A GENETIC AND METABOLIC
29 SCREENING DEFINED. Genetic and metabolic screening means
30 the search through testing for persons with genetic and
31 metabolic diseases so that early treatment or counseling can
32 lead to the amelioration or avoidance of the adverse
33 consequences of the diseases.

34 Sec. 4. Section 136A.3, Code 1983, is amended to read
35 as follows:

1 136A.3 ACTIVITIES OF THE INSTITUTE. The birth defects
2 institute may:

3 1. Conduct scientific investigations and surveys of the
4 causes, mortality, methods of treatment, prevention and cure
5 of birth defects.

6 2. Publish the results of ~~such~~ the investigations and
7 surveys for the benefit of the public health and collate ~~such~~
8 the publications for distribution to scientific organizations
9 and qualified scientists and physicians.

10 3. Develop and administer genetic and metabolic screening
11 programs to detect and prevent or treat birth defects, the
12 programs to be conducted throughout the state.

13 4. Develop specifications for and designate a central
14 laboratory in which tests required pursuant to the screening
15 programs required in subsection 3 will be performed, taking
16 into account the test costs to the financially responsible
17 private parties and to the state.

18 3 5. Implement programs of professional education and
19 training of medical students, physicians, nurses, scientists
20 and technicians in the causes, methods of treatment, prevention
21 and cure of birth defects.

22 6. Implement public educational programs to inform persons
23 of the importance of genetic screening and of the various
24 opportunities available.

25 4 7. Conduct and support clinical counseling services
26 in medical facilities.

27 Sec. 5. NEW SECTION. 136A.4 RULES, REGULATIONS, AND
28 STANDARDS. The birth defects institute, with assistance pro-
29 vided by the state department of health, shall adopt rules
30 pursuant to chapter 17A to implement this chapter.

31 Sec. 6. NEW SECTION. 136A.5 CENTRAL REGISTRY--
32 CONFIDENTIALITY. The birth defects institute may maintain
33 a central registry to collect and store report data to
34 facilitate the compiling of statistical information on the
35 causes, treatment, prevention, and cure of genetic disorders

1 and birth defects. Identifying information shall remain
2 confidential pursuant to section 68A.7, subsection 2.

3 Sec. 7. NEW SECTION. 136A.6 COOPERATION OF OTHER
4 AGENCIES. All state, district, county, and city health or
5 welfare agencies shall cooperate and participate in the
6 implementation of this chapter.

7 Sec. 8. Section 135.31 and chapter 141, Code 1983, are
8 repealed.

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SEVENTIETH GENERAL ASSEMBLY

1983 REGULAR SESSION

DAILY

SENATE CLIP SHEET

FRIDAY, FEBRUARY 25, 1983

SENATE FILE 188

FISCAL NOTE

REQUESTED BY SENATOR SCHWENGELS

In compliance with a written request there is hereby submitted a Fiscal Note for Senate File 188 pursuant to Joint Rule 17.

Senate File 188 expands the responsibility of the birth defects institute within the state department of health. The institute shall develop and administer screening programs for genetic and metabolic defects or disease.

The bill permits the birth defects institute to designate a central laboratory to perform the necessary testing and to maintain a confidential central registry for the compilation of data. Tests will be performed to identify four disorders which have a common outcome of mental retardation. Under the proposed law, an estimated 45,000 children will be tested annually. The program will be financed from patient fees and third party payers.

	FY '84	FY '85
Cost of program	\$ 562,500	618,750
Revenues generated	562,500	618,750
Total annual impact	\$ 0	0

In addition, a study by the Health Dept. in 1982 estimated it costs \$500,000 for lifelong support of one developmentally disabled citizen. The fiscal benefits of averting genetic or metabolic diseases can be derived as such:

\$ 500,000	Support cost for one developmentally disabled citizen
x 14	Affected newborns identified annually
<u>\$7,000,000</u>	Total savings per year

This figure can be interpreted to mean that for every dollar spent in the screening program in FY '84, there is a potential savings of \$12.44. (189S, 83-176, KAC)

SOURCE: DEPARTMENT OF HEALTH

FILED:
FEBRUARY 24, 1983

BY LEGISLATIVE FISCAL BUREAU
DENNIS C. PROUTY, DIRECTOR

SENATE FILE 188

AN ACT

RELATING TO THE BIRTH DEFECTS INSTITUTE WITHIN THE STATE
DEPARTMENT OF HEALTH.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

Section 1. Section 136A.1, Code 1983, is amended to read as follows:

136A.1 PURPOSE. In order to provide for the protection and promotion of the health of the inhabitants of the state, the state department of health shall ~~have the responsibility for the development~~ develop and administer the state's policy with respect to the conduct of scientific investigations and research concerning the causes, prevention, treatment and cure of birth defects. The department shall initiate, conduct, and supervise screening programs to discover genetic birth defects and related diseases and to prevent or treat the defects or diseases.

Sec. 2. Section 136A.2, Code 1983, is amended to read as follows:

136A.2 ESTABLISHMENT OF BIRTH DEFECTS INSTITUTE. There is established within the state department of health a birth defects institute ~~for the purposes of initiating to initiate and conducting~~ conduct investigations of the causes, mortality, methods of treatment, prevention and cure of birth defects and related diseases and to develop and administer genetic and metabolic screening programs and other related activities where the programs will aid in the prevention or treatment of a particular genetic or metabolic defect or disease. The birth defects institute shall assume responsibility for development and implementation of screening and educational programs for sickle cell anemia and other genetic blood disorders.

Sec. 3. NEW SECTION. 136A.2A GENETIC AND METABOLIC SCREENING DEFINED. Genetic and metabolic screening means the search through testing for persons with genetic and metabolic diseases so that early treatment or counseling can lead to the amelioration or avoidance of the adverse consequences of the diseases.

Sec. 4. Section 136A.3, Code 1983, is amended to read as follows:

136A.3 ACTIVITIES OF THE INSTITUTE. The birth defects institute may:

1. Conduct scientific investigations and surveys of the causes, mortality, methods of treatment, prevention and cure of birth defects.

2. Publish the results of such the investigations and surveys for the benefit of the public health and collate such the publications for distribution to scientific organizations and qualified scientists and physicians.

3. Develop and administer genetic and metabolic screening programs to detect and prevent or treat birth defects, the programs to be conducted throughout the state.

4. Develop specifications for and designate a central laboratory in which tests required pursuant to the screening programs required in subsection 3 will be performed, taking into account the test costs to the financially responsible private parties and to the state.

5. Implement programs of professional education and training of medical students, physicians, nurses, scientists and technicians in the causes, methods of treatment, prevention and cure of birth defects.

6. Implement public educational programs to inform persons of the importance of genetic screening and of the various opportunities available.

7. Conduct and support clinical counseling services in medical facilities.

Sec. 5. NEW SECTION. 136A.4 RULES, REGULATIONS, AND STANDARDS. The birth defects institute, with assistance provided by the state department of health, shall adopt rules pursuant to chapter 17A to implement this chapter.

Sec. 6. NEW SECTION. 136A.5 CENTRAL REGISTRY--
CONFIDENTIALITY. The birth defects institute may maintain
a central registry to collect and store report data to
facilitate the compiling of statistical information on the
causes, treatment, prevention, and cure of genetic disorders
and birth defects. Identifying information shall remain
confidential pursuant to section 68A.7, subsection 2.

Sec. 7. NEW SECTION. 136A.6 COOPERATION OF OTHER
AGENCIES. All state, district, county, and city health or
welfare agencies shall cooperate and participate in the
implementation of this chapter.

Sec. 8. Section 135.31 and chapter 141, Code 1983, are
repealed.

ROBERT T. ANDERSON
President of the Senate

DONALD D. AVENSON
Speaker of the House

I hereby certify that this bill originated in the Senate and
is known as Senate File 188, Seventieth General Assembly.

K. MARIE THAYER
Secretary of the Senate

Approved April 21, 1983

TERRY E. BRANSTAD
Governor