

JAN 23 2004  
HUMAN RESOURCES

HOUSE FILE 2074  
BY PETERSEN, CARROLL,  
HEDDENS, HUSER,  
and UPMEYER

Passed House, Date \_\_\_\_\_ Passed Senate, Date \_\_\_\_\_  
Vote: Ayes \_\_\_\_\_ Nays \_\_\_\_\_ Vote: Ayes \_\_\_\_\_ Nays \_\_\_\_\_  
Approved \_\_\_\_\_

**A BILL FOR**

1 An Act relating to the duties of the birth defects institute by  
2 providing for a work group to study stillbirths and renaming  
3 the institute.

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

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HF 2074

1 Section 1. LEGISLATIVE INTENT AND PURPOSE -- STILLBIRTHS  
2 PROTOCOL WORK GROUP.

3 1. It is the intent of the general assembly that the  
4 department of public health study and develop prevention  
5 strategies to reduce stillbirths and other congenital or  
6 inherited disorders which cause the death and disability of  
7 newborns in this state. It is the purpose of this Act to  
8 enable the department to carry out the intent of the general  
9 assembly through a stillbirths protocol work group and the  
10 redesign of the birth defects institute.

11 2. The Iowa department of public health shall establish a  
12 work group to develop protocol and implementation guidelines  
13 for the evaluation of causes and prevention of stillbirths by  
14 the center for congenital and inherited disorders. The  
15 director of public health shall select the members of the work  
16 group, which may include representatives from the child death  
17 review team, the Iowa hospital association, the health care  
18 industry, the health insurance industry, and parents or other  
19 interested parties as deemed appropriate by the director. The  
20 director shall submit a report from the work group to the  
21 general assembly on or before January 15, 2005.

22 Sec. 2. NEW SECTION. 136E.1 PURPOSE.

23 To reduce and avoid adverse health conditions of  
24 inhabitants of the state, the Iowa department of public health  
25 shall initiate, conduct, and supervise screening and health  
26 care programs in order to detect and predict congenital or  
27 inherited disorders. The department shall assist in the  
28 translation and integration of genetic and genomic advances  
29 into public health services to improve health outcomes  
30 throughout the life span of the inhabitants of the state.

31 Sec. 3. NEW SECTION. 136E.2 DEFINITIONS.

32 As used in this chapter, unless the context otherwise  
33 requires:

34 1. "Attending health care provider" means a licensed  
35 physician, nurse practitioner, certified nurse midwife, or

1 physician assistant.

2 2. "Congenital disorder" means an abnormality existing  
3 prior to or at birth, including a stillbirth, that adversely  
4 affects the health and development of a fetus, newborn, child,  
5 or adult, including a structural malformation or a genetic,  
6 chromosomal, inherited, or biochemical disorder.

7 3. "Department" means the Iowa department of public  
8 health.

9 4. "Disorder" means a congenital or inherited disorder.

10 5. "Genetics" means the study of inheritance and how genes  
11 contribute to health conditions and the potential for disease.

12 6. "Genomics" mean the functions and interactions of all  
13 human genes and their variation within human populations,  
14 including their interaction with environmental factors, and  
15 their contribution to health.

16 7. "Inherited disorder" means a condition caused by an  
17 abnormal change in a gene or genes passed from a parent or  
18 parents to their child. Onset of the disorder may be prior to  
19 or at birth, during childhood, or in adulthood.

20 8. "Stillbirth" means an unintended fetal death occurring  
21 after a gestation period of twenty completed weeks, or an  
22 unintended fetal death of a fetus with a weight of three  
23 hundred fifty or more grams.

24 Sec. 4. NEW SECTION. 136E.3 ESTABLISHMENT OF CENTER FOR  
25 CONGENITAL AND INHERITED DISORDERS -- DUTIES.

26 A center for congenital and inherited disorders is  
27 established within the department. The center shall do all of  
28 the following:

29 1. Initiate, conduct, and supervise statewide screening  
30 programs for congenital and inherited disorders amenable to  
31 population screening.

32 2. Initiate, conduct, and supervise statewide health care  
33 programs to aid in the early detection, treatment, prevention,  
34 education, and provision of supportive care related to  
35 congenital and inherited disorders.

1        3. Develop specifications for and designate a central  
2 laboratory in which tests conducted pursuant to the screening  
3 programs provided for in subsection 1 will be performed.

4        4. Gather, evaluate, and maintain information related to  
5 causes, severity, prevention, and methods of treatment for  
6 congenital and inherited disorders in conjunction with a  
7 central registry, screening programs, genetic health care  
8 programs, and ongoing scientific investigations and surveys.

9        5. Perform surveillance and monitoring of congenital and  
10 inherited disorders to determine the occurrence and trends of  
11 the disorders, to conduct thorough and complete  
12 epidemiological surveys, to assist in the planning for and  
13 provision of services to children with congenital and  
14 inherited disorders and their families, and to identify  
15 environmental and genetic risk factors for congenital and  
16 inherited disorders.

17       6. Provide information related to severity, causes,  
18 prevention, and methods of treatment for congenital and  
19 inherited disorders to the public, medical and scientific  
20 communities, and health science disciplines.

21       7. Implement public education programs, continuing  
22 education programs for health practitioners, and education  
23 programs for trainees of the health science disciplines  
24 related to genetics, congenital disorders, and inheritable  
25 disorders.

26       8. Participate in policy development to assure the  
27 appropriate use and confidentiality of genetic information and  
28 technologies to improve health and prevent disease.

29       9. Collaborate with state and local health agencies and  
30 other public and private organizations to provide education,  
31 intervention, and treatment for congenital and inherited  
32 disorders and to integrate genetics and genomics advances into  
33 public health activities and policies.

34       Sec. 5. NEW SECTION. 136E.4 GENETIC HEALTH SERVICES.

35       The center may initiate, conduct, and supervise genetic

1 health services for the inhabitants of the state, including  
2 the provision of regional genetic consultation clinics,  
3 comprehensive neuromuscular health care outreach clinics, and  
4 other outreach services and clinics as established by rule.

5 Sec. 6. NEW SECTION. 136E.5 NEWBORN METABOLIC SCREENING.

6 1. All newborns and stillborns born in this state shall be  
7 screened for congenital and inherited disorders in accordance  
8 with rules adopted by the department.

9 2. An attending health care provider shall ensure that  
10 every newborn and stillborn under the provider's care is  
11 screened for congenital and inherited disorders in accordance  
12 with rules adopted by the department.

13 3. This section does not apply if the parent objects to  
14 the screening. If a parent objects to the screening of a  
15 newborn, the attending health care provider shall document the  
16 refusal in the newborn's medical record and shall obtain a  
17 written refusal from the parent and report the refusal to the  
18 department as provided by rule of the department.

19 Sec. 7. NEW SECTION. 136E.6 CENTRAL REGISTRY.

20 The center for congenital and inherited disorders shall  
21 maintain a central registry, or shall establish an agreement  
22 with a designated contractor to maintain a central registry,  
23 to compile, evaluate, retain, and disseminate information on  
24 the occurrence, prevalence, causes, treatment, and prevention  
25 of congenital disorders. Congenital disorders shall be  
26 considered reportable conditions in accordance with rules  
27 adopted by the department and shall be abstracted and  
28 maintained by the registry.

29 Sec. 8. NEW SECTION. 136E.7 CONFIDENTIALITY.

30 The center for congenital and inherited disorders and the  
31 department shall maintain the confidentiality of any  
32 identifying information collected, used, or maintained  
33 pursuant to this chapter in accordance with section 22.7,  
34 subsection 2.

35 Sec. 9. NEW SECTION. 136E.8 RULES.

1 The center for congenital and inherited disorders, with  
2 assistance provided by the Iowa department of public health,  
3 shall adopt rules pursuant to chapter 17A to administer this  
4 chapter.

5 Sec. 10. NEW SECTION. 136E.9 COOPERATION OF OTHER  
6 AGENCIES.

7 All state, district, county, and city health or welfare  
8 agencies shall cooperate and participate in the administration  
9 of this chapter.

10 Sec. 11. Chapter 136A, Code 2003, is repealed.

11 Sec. 12. CODE EDITOR DIRECTIVE.

12 1. The Code editor may transfer chapter 136E to chapter  
13 136A.

14 2. The Code editor is directed to strike the words "birth  
15 defects institute" and insert the words "center for congenital  
16 and inherited disorders" where the words appear in section  
17 144.13A.

18 3. The Code editor shall correct any references to the  
19 center for congenital and inherited disorders as the successor  
20 to the birth defects institute, including grammatical  
21 constructions, anywhere else in the Code, in any bills  
22 awaiting codification, and in any bills enacted by the  
23 Eightieth General Assembly, 2004 Regular Session.

24 EXPLANATION

25 This bill relates to the duties of the birth defects  
26 institute established in Code chapter 136A by providing for a  
27 work group to study stillbirths and by renaming the institute.

28 A work group is required to be created by the Iowa  
29 department of public health to develop protocol and  
30 implementation guidelines for the evaluation of causes and  
31 prevention of stillbirths. Members of the work group will be  
32 selected by the director of public health who must report the  
33 results of the work group to the general assembly by January  
34 15, 2005.

35 The bill renames the birth defects institute the center for

1 congenital and inherited disorders. The bill expands the  
2 institute's scope of study beyond birth defects to include the  
3 study of the causes and prevention of all congenital and  
4 inherited disorders, including stillbirths. The center will  
5 continue the duties of the institute to maintain a central  
6 registry, conduct screening programs, provide statewide health  
7 care programs, and provide information to and educate the  
8 public and medical and scientific communities. The center may  
9 provide genetic health services through clinics or outreach  
10 services. The bill permits parents the option to refuse  
11 screening for their child.

12 The bill provides for confidentiality of identifiable  
13 information collected, used, or maintained by the center or  
14 department and provides the center authority to adopt rules.

15 The Code editor is directed to make all necessary changes  
16 to existing provisions of the Code and prospective enactments  
17 by the general assembly to codify the new Code chapter.

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# Fiscal Services Division

## Legislative Services Agency

### Fiscal Note

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HF 2074 - Stillbirth Reporting (LSB 5237 YH)

Analyst: Lisa Burk (Phone: (515) 281-7942) (lisa.burk@legis.state.ia.us)

Fiscal Note Version - New

Requested by Representative Janet Petersen

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#### Description

House File 2074 renames the Birth Defects Institute to the Center for Congenital and Inherited Disorders and expands the Center's duties to include the study of the causes and prevention of all congenital and inherited disorders, including stillbirths. In addition, the Bill requires the Department of Public Health to establish a work group to develop protocol and implementation guidelines for the evaluation of causes and prevention of stillbirths and requires the results of the work group be submitted in a report to the General Assembly by January 15, 2005.

#### Assumptions

1. The work group will consist of up to 15 volunteer members and will meet four times in FY 2005.
2. The work group will study and adapt the protocols and implementation guidelines used by the Wisconsin Stillbirth Service Program for use by the Center for Congenital and Inherited Disorders.
3. The Center will have additional duties and costs associated with stillbirth assessments, including, but not limited to, data management, clinical examinations, review of medical charts, prenatal history, and maternal risk factors, as well as diagnostic assessment, interpretation, and summary.
4. The estimated cost for a comprehensive stillbirth assessment will be \$1,500 per evaluation.
5. Fetal death, or stillbirth, is defined as a baby born after 20 gestational weeks or that weighs 350 grams.
6. The State recorded an annual average of 205 fetal deaths from Calendar Year 2000 to 2002. Using the average of 205, it is estimated that 32 (15.8%) of these will be referred to the Center for assessment per year.
7. It is unknown how many of the 91 birthing hospitals in the State will choose to participate in offering to refer cases to the Center, and it is also unknown how many parents will wish to have cases referred to the Center.
8. The Department of Public Health will have support costs associated with scheduling workgroup meetings, including per diem costs for some workgroup members, and in preparing the required report in FY 2005. In addition, the Department will have costs associated with conducting educational outreach for hospitals that choose to participate during the last half of FY 2005 and in FY 2006.
9. The initial contact with hospitals regarding participation will be done by telephone or mail. If a hospital expresses interest in participating after the initial contact is made, education will be scheduled. In some cases, it may be possible to educate several hospitals at one time in a central location.
10. The Bureau of Vital Statistics, Department of Public Health, which is currently required to collect and preserve statistics related to records of fetal death by Section 144.29, Code of Iowa, will not do case identification, data management related to the Program, or make case referrals to the Center.

**Fiscal Impact**

House File 2074 is estimated to have a fiscal impact of \$28,000 to the Department of Public Health in FY 2005. In FY 2006, the Bill is estimated to have a combined fiscal impact of \$86,000 to the Department of Public Health and the Center for Congenital and Inherited Disorders. The table below outlines these costs.

<u>State</u>	<u>Year 1 FY 2005</u>	<u>Year 2 FY 2006</u>
Public Health		
Workgroup Meetings	\$ 3,000	\$ 0
Required Report	5,000	0
Educational Outreach	20,000	30,000
Center		
Case Assessments	0	48,000
Database Management	0	8,000
<b>Total</b>	<u>\$ 28,000</u>	<u>\$ 86,000</u>

The amounts provided in the above chart are additional General Fund expenses that will not be absorbed within the Department's and the Center's existing budgets.

**Sources**

Department of Public Health, Bureau of Vital Statistics  
Legislative Services Agency, Fiscal Services Division  
University of Wisconsin - Madison, Clinical Genetics Center

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Dennis C Prouty

February 24, 2004

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The fiscal note and correctional impact statement for this bill was prepared pursuant to Joint Rule 17 and pursuant to Section 2.56, Code of Iowa. Data used in developing this fiscal note and correctional impact statement are available from the Fiscal Services Division, Legislative Services Agency to members of the Legislature upon request.

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