

# House File 2362

HOUSE FILE  
BY COMMITTEE ON HUMAN RESOURCES

(SUCCESSOR TO HF 2074)

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:  
5 TLSB 5237HV 80  
6 kk/gg/14

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1 1 Section 1. LEGISLATIVE INTENT AND PURPOSE == STILLBIRTHS  
1 2 PROTOCOL WORK GROUP.  
1 3 1. It is the intent of the general assembly that the  
1 4 department of public health study and develop prevention  
1 5 strategies to reduce stillbirths and other congenital or  
1 6 inherited disorders which cause the death and disability of  
1 7 newborns in this state. It is the purpose of this Act to  
1 8 enable the department to carry out the intent of the general  
1 9 assembly through a stillbirths protocol work group and the  
1 10 redesign of the birth defects institute.  
1 11 2. The Iowa department of public health shall establish a  
1 12 work group to develop protocol and implementation guidelines  
1 13 for the evaluation of causes and prevention of stillbirths  
1 14 including environmental and maternal factors. The director of  
1 15 public health shall select the members of the work group,  
1 16 which may include representatives from the child death review  
1 17 team, the health care industry, the health insurance industry,  
1 18 and parents or other interested parties as deemed appropriate  
1 19 by the director. The director shall submit a report from the  
1 20 work group to the general assembly on or before July 15, 2005.  
1 21 Sec. 2. NEW SECTION. 136E.1 PURPOSE.  
1 22 To reduce and avoid adverse health conditions of  
1 23 inhabitants of the state, the Iowa department of public health  
1 24 shall initiate, conduct, and supervise screening and health  
1 25 care programs in order to detect and predict congenital or  
1 26 inherited disorders. The department shall assist in the  
1 27 translation and integration of genetic and genomic advances  
1 28 into public health services to improve health outcomes  
1 29 throughout the life span of the inhabitants of the state.  
1 30 Sec. 3. NEW SECTION. 136E.2 DEFINITIONS.  
1 31 As used in this chapter, unless the context otherwise  
1 32 requires:  
1 33 1. "Attending health care provider" means a licensed

1 34 physician, nurse practitioner, certified nurse midwife, or  
1 35 physician assistant.

2 1 2. "Congenital disorder" means an abnormality existing  
2 2 prior to or at birth, including a stillbirth, that adversely  
2 3 affects the health and development of a fetus, newborn, child,  
2 4 or adult, including a structural malformation or a genetic,  
2 5 chromosomal, inherited, or biochemical disorder.

2 6 3. "Department" means the Iowa department of public  
2 7 health.

2 8 4. "Disorder" means a congenital or inherited disorder.

2 9 5. "Genetics" means the study of inheritance and how genes  
2 10 contribute to health conditions and the potential for disease.

2 11 6. "Genomics" mean the functions and interactions of all  
2 12 human genes and their variation within human populations,  
2 13 including their interaction with environmental factors, and  
2 14 their contribution to health.

2 15 7. "Inherited disorder" means a condition caused by an  
2 16 abnormal change in a gene or genes passed from a parent or  
2 17 parents to their child. Onset of the disorder may be prior to  
2 18 or at birth, during childhood, or in adulthood.

2 19 8. "Stillbirth" means an unintended fetal death occurring  
2 20 after a gestation period of twenty completed weeks, or an  
2 21 unintended fetal death of a fetus with a weight of three  
2 22 hundred fifty or more grams.

2 23 Sec. 4. NEW SECTION. 136E.3 ESTABLISHMENT OF CENTER FOR  
2 24 CONGENITAL AND INHERITED DISORDERS == DUTIES.

2 25 A center for congenital and inherited disorders is  
2 26 established within the department. The center shall do all of  
2 27 the following:

2 28 1. Initiate, conduct, and supervise statewide screening  
2 29 programs for congenital and inherited disorders amenable to  
2 30 population screening.

2 31 2. Initiate, conduct, and supervise statewide health care  
2 32 programs to aid in the early detection, treatment, prevention,  
2 33 education, and provision of supportive care related to  
2 34 congenital and inherited disorders.

2 35 3. Develop specifications for and designate a central  
3 1 laboratory in which tests conducted pursuant to the screening  
3 2 programs provided for in subsection 1 will be performed.

3 3 4. Gather, evaluate, and maintain information related to  
3 4 causes, severity, prevention, and methods of treatment for  
3 5 congenital and inherited disorders in conjunction with a  
3 6 central registry, screening programs, genetic health care  
3 7 programs, and ongoing scientific investigations and surveys.

3 8 5. Perform surveillance and monitoring of congenital and  
3 9 inherited disorders to determine the occurrence and trends of  
3 10 the disorders, to conduct thorough and complete  
3 11 epidemiological surveys, to assist in the planning for and  
3 12 provision of services to children with congenital and  
3 13 inherited disorders and their families, and to identify  
3 14 environmental and genetic risk factors for congenital and  
3 15 inherited disorders.

3 16 6. Provide information related to severity, causes,  
3 17 prevention, and methods of treatment for congenital and  
3 18 inherited disorders to the public, medical and scientific  
3 19 communities, and health science disciplines.

3 20 7. Implement public education programs, continuing

3 21 education programs for health practitioners, and education  
3 22 programs for trainees of the health science disciplines  
3 23 related to genetics, congenital disorders, and inheritable  
3 24 disorders.

3 25 8. Participate in policy development to assure the  
3 26 appropriate use and confidentiality of genetic information and  
3 27 technologies to improve health and prevent disease.

3 28 9. Collaborate with state and local health agencies and  
3 29 other public and private organizations to provide education,  
3 30 intervention, and treatment for congenital and inherited  
3 31 disorders and to integrate genetics and genomics advances into  
3 32 public health activities and policies.

3 33 Sec. 5. NEW SECTION. 136E.4 GENETIC HEALTH SERVICES.

3 34 The center may initiate, conduct, and supervise genetic  
3 35 health services for the inhabitants of the state, including  
4 1 the provision of regional genetic consultation clinics,  
4 2 comprehensive neuromuscular health care outreach clinics, and  
4 3 other outreach services and clinics as established by rule.

4 4 Sec. 6. NEW SECTION. 136E.5 NEWBORN METABOLIC SCREENING.

4 5 1. All newborns born in this state shall be screened for  
4 6 congenital and inherited disorders in accordance with rules  
4 7 adopted by the department.

4 8 2. An attending health care provider shall ensure that  
4 9 every newborn under the provider's care is screened for  
4 10 congenital and inherited disorders in accordance with rules  
4 11 adopted by the department.

4 12 3. This section does not apply if the parent objects to  
4 13 the screening. If a parent objects to the screening of a  
4 14 newborn, the attending health care provider shall document the  
4 15 refusal in the newborn's medical record and shall obtain a  
4 16 written refusal from the parent and report the refusal to the  
4 17 department as provided by rule of the department.

4 18 Sec. 7. NEW SECTION. 136E.6 CENTRAL REGISTRY.

4 19 The center for congenital and inherited disorders shall  
4 20 maintain a central registry, or shall establish an agreement  
4 21 with a designated contractor to maintain a central registry,  
4 22 to compile, evaluate, retain, and disseminate information on  
4 23 the occurrence, prevalence, causes, treatment, and prevention  
4 24 of congenital disorders. Congenital disorders shall be  
4 25 considered reportable conditions in accordance with rules  
4 26 adopted by the department and shall be abstracted and  
4 27 maintained by the registry.

4 28 Sec. 8. NEW SECTION. 136E.7 CONFIDENTIALITY.

4 29 The center for congenital and inherited disorders and the  
4 30 department shall maintain the confidentiality of any  
4 31 identifying information collected, used, or maintained  
4 32 pursuant to this chapter in accordance with section 22.7,  
4 33 subsection 2.

4 34 Sec. 9. NEW SECTION. 136E.8 RULES.

4 35 The center for congenital and inherited disorders, with  
5 1 assistance provided by the Iowa department of public health,  
5 2 shall adopt rules pursuant to chapter 17A to administer this  
5 3 chapter.

5 4 Sec. 10. NEW SECTION. 136E.9 COOPERATION OF OTHER  
5 5 AGENCIES.

5 6 All state, district, county, and city health or welfare  
5 7 agencies shall cooperate and participate in the administration

5 8 of this chapter.

5 9 Sec. 11. Chapter 136A, Code 2003, is repealed.

5 10 Sec. 12. CODE EDITOR DIRECTIVE.

5 11 1. The Code editor may transfer chapter 136E to chapter  
5 12 136A.

5 13 2. The Code editor is directed to strike the words "birth  
5 14 defects institute" and insert the words "center for congenital  
5 15 and inherited disorders" where the words appear in section  
5 16 144.13A.

5 17 3. The Code editor shall correct any references to the  
5 18 center for congenital and inherited disorders as the successor  
5 19 to the birth defects institute, including grammatical  
5 20 constructions, anywhere else in the Code, in any bills  
5 21 awaiting codification, and in any bills enacted by the  
5 22 Eightieth General Assembly, 2004 Regular Session.

5 23 EXPLANATION

5 24 This bill relates to the duties of the birth defects  
5 25 institute established in Code chapter 136A by providing for a  
5 26 work group to study stillbirths and by renaming the institute.

5 27 A work group is required to be created by the Iowa  
5 28 department of public health to develop protocol and  
5 29 implementation guidelines for the evaluation of causes and  
5 30 prevention of stillbirths. Members of the work group will be  
5 31 selected by the director of public health who must report the  
5 32 results of the work group to the general assembly by July 15,  
5 33 2005.

5 34 The bill renames the birth defects institute the center for  
5 35 congenital and inherited disorders. The bill expands the  
6 1 institute's scope of study beyond birth defects to include the  
6 2 study of the causes and prevention of all congenital and  
6 3 inherited disorders, including stillbirths. The center will  
6 4 continue the duties of the institute to maintain a central  
6 5 registry, conduct screening programs, provide statewide health  
6 6 care programs, and provide information to and educate the  
6 7 public and medical and scientific communities. The center may  
6 8 provide genetic health services through clinics or outreach  
6 9 services. The bill permits parents the option to refuse  
6 10 screening for their child.

6 11 The bill provides for confidentiality of identifiable  
6 12 information collected, used, or maintained by the center or  
6 13 department and provides the center authority to adopt rules.

6 14 The Code editor is directed to make all necessary changes  
6 15 to existing provisions of the Code and prospective enactments  
6 16 by the general assembly to codify the new Code chapter.

6 17 LSB 5237HV 80

6 18 kk/gg/14