

# House File 2362

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1 3 AN ACT  
1 4 RELATING TO THE DUTIES OF THE BIRTH DEFECTS INSTITUTE BY  
1 5 PROVIDING FOR A WORK GROUP TO STUDY STILLBIRTHS AND RENAMING  
1 6 THE INSTITUTE.  
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1 8 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:  
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1 10 Section 1. LEGISLATIVE INTENT AND PURPOSE == STILLBIRTHS  
1 11 PROTOCOL WORK GROUP.  
1 12 1. It is the intent of the general assembly that the  
1 13 department of public health study and develop prevention  
1 14 strategies to reduce stillbirths and other congenital or  
1 15 inherited disorders which cause the death and disability of  
1 16 newborns in this state. It is the purpose of this Act to  
1 17 enable the department to carry out the intent of the general  
1 18 assembly through a stillbirths protocol work group and the  
1 19 redesign of the birth defects institute.  
1 20 2. The Iowa department of public health shall establish a  
1 21 work group to develop protocol and implementation guidelines  
1 22 for the evaluation of causes and prevention of stillbirths  
1 23 including environmental and maternal factors. The director of  
1 24 public health shall select the members of the work group,  
1 25 which may include representatives from the child death review  
1 26 team, the health care industry, the health insurance industry,  
1 27 and parents or other interested parties as deemed appropriate  
1 28 by the director. The director shall submit a report from the  
1 29 work group to the general assembly on or before July 15, 2005.  
1 30 Sec. 2. NEW SECTION. 136E.1 PURPOSE.  
1 31 To reduce and avoid adverse health conditions of  
1 32 inhabitants of the state, the Iowa department of public health  
1 33 shall initiate, conduct, and supervise screening and health  
1 34 care programs in order to detect and predict congenital or  
1 35 inherited disorders. The department shall assist in the  
2 1 translation and integration of genetic and genomic advances  
2 2 into public health services to improve health outcomes  
2 3 throughout the life span of the inhabitants of the state.  
2 4 Sec. 3. NEW SECTION. 136E.2 DEFINITIONS.  
2 5 As used in this chapter, unless the context otherwise  
2 6 requires:  
2 7 1. "Attending health care provider" means a licensed  
2 8 physician, nurse practitioner, certified nurse midwife, or  
2 9 physician assistant.  
2 10 2. "Congenital disorder" means an abnormality existing  
2 11 prior to or at birth, including a stillbirth, that adversely  
2 12 affects the health and development of a fetus, newborn, child,  
2 13 or adult, including a structural malformation or a genetic,  
2 14 chromosomal, inherited, or biochemical disorder.  
2 15 3. "Department" means the Iowa department of public  
2 16 health.  
2 17 4. "Disorder" means a congenital or inherited disorder.  
2 18 5. "Genetics" means the study of inheritance and how genes  
2 19 contribute to health conditions and the potential for disease.  
2 20 6. "Genomics" mean the functions and interactions of all  
2 21 human genes and their variation within human populations,  
2 22 including their interaction with environmental factors, and  
2 23 their contribution to health.  
2 24 7. "Inherited disorder" means a condition caused by an  
2 25 abnormal change in a gene or genes passed from a parent or  
2 26 parents to their child. Onset of the disorder may be prior to  
2 27 or at birth, during childhood, or in adulthood.  
2 28 8. "Stillbirth" means an unintended fetal death occurring  
2 29 after a gestation period of twenty completed weeks, or an  
2 30 unintended fetal death of a fetus with a weight of three  
2 31 hundred fifty or more grams.  
2 32 Sec. 4. NEW SECTION. 136E.3 ESTABLISHMENT OF CENTER FOR  
2 33 CONGENITAL AND INHERITED DISORDERS == DUTIES.  
2 34 A center for congenital and inherited disorders is  
2 35 established within the department. The center shall do all of  
3 1 the following:  
3 2 1. Initiate, conduct, and supervise statewide screening  
3 3 programs for congenital and inherited disorders amenable to  
3 4 population screening.  
3 5 2. Initiate, conduct, and supervise statewide health care

3 6 programs to aid in the early detection, treatment, prevention,  
3 7 education, and provision of supportive care related to  
3 8 congenital and inherited disorders.

3 9 3. Develop specifications for and designate a central  
3 10 laboratory in which tests conducted pursuant to the screening  
3 11 programs provided for in subsection 1 will be performed.

3 12 4. Gather, evaluate, and maintain information related to  
3 13 causes, severity, prevention, and methods of treatment for  
3 14 congenital and inherited disorders in conjunction with a  
3 15 central registry, screening programs, genetic health care  
3 16 programs, and ongoing scientific investigations and surveys.

3 17 5. Perform surveillance and monitoring of congenital and  
3 18 inherited disorders to determine the occurrence and trends of  
3 19 the disorders, to conduct thorough and complete  
3 20 epidemiological surveys, to assist in the planning for and  
3 21 provision of services to children with congenital and  
3 22 inherited disorders and their families, and to identify  
3 23 environmental and genetic risk factors for congenital and  
3 24 inherited disorders.

3 25 6. Provide information related to severity, causes,  
3 26 prevention, and methods of treatment for congenital and  
3 27 inherited disorders to the public, medical and scientific  
3 28 communities, and health science disciplines.

3 29 7. Implement public education programs, continuing  
3 30 education programs for health practitioners, and education  
3 31 programs for trainees of the health science disciplines  
3 32 related to genetics, congenital disorders, and inheritable  
3 33 disorders.

3 34 8. Participate in policy development to assure the  
3 35 appropriate use and confidentiality of genetic information and  
4 1 technologies to improve health and prevent disease.

4 2 9. Collaborate with state and local health agencies and  
4 3 other public and private organizations to provide education,  
4 4 intervention, and treatment for congenital and inherited  
4 5 disorders and to integrate genetics and genomics advances into  
4 6 public health activities and policies.

4 7 Sec. 5. NEW SECTION. 136E.4 GENETIC HEALTH SERVICES.

4 8 The center may initiate, conduct, and supervise genetic  
4 9 health services for the inhabitants of the state, including  
4 10 the provision of regional genetic consultation clinics,  
4 11 comprehensive neuromuscular health care outreach clinics, and  
4 12 other outreach services and clinics as established by rule.

4 13 Sec. 6. NEW SECTION. 136E.5 NEWBORN METABOLIC SCREENING.

4 14 1. All newborns born in this state shall be screened for  
4 15 congenital and inherited disorders in accordance with rules  
4 16 adopted by the department.

4 17 2. An attending health care provider shall ensure that  
4 18 every newborn under the provider's care is screened for  
4 19 congenital and inherited disorders in accordance with rules  
4 20 adopted by the department.

4 21 3. This section does not apply if the parent objects to  
4 22 the screening. If a parent objects to the screening of a  
4 23 newborn, the attending health care provider shall document the  
4 24 refusal in the newborn's medical record and shall obtain a  
4 25 written refusal from the parent and report the refusal to the  
4 26 department as provided by rule of the department.

4 27 Sec. 7. NEW SECTION. 136E.6 CENTRAL REGISTRY.

4 28 The center for congenital and inherited disorders shall  
4 29 maintain a central registry, or shall establish an agreement  
4 30 with a designated contractor to maintain a central registry,  
4 31 to compile, evaluate, retain, and disseminate information on  
4 32 the occurrence, prevalence, causes, treatment, and prevention  
4 33 of congenital disorders. Congenital disorders shall be  
4 34 considered reportable conditions in accordance with rules  
4 35 adopted by the department and shall be abstracted and  
5 1 maintained by the registry.

5 2 Sec. 8. NEW SECTION. 136E.7 CONFIDENTIALITY.

5 3 The center for congenital and inherited disorders and the  
5 4 department shall maintain the confidentiality of any  
5 5 identifying information collected, used, or maintained  
5 6 pursuant to this chapter in accordance with section 22.7,  
5 7 subsection 2.

5 8 Sec. 9. NEW SECTION. 136E.8 RULES.

5 9 The center for congenital and inherited disorders, with  
5 10 assistance provided by the Iowa department of public health,  
5 11 shall adopt rules pursuant to chapter 17A to administer this  
5 12 chapter.

5 13 Sec. 10. NEW SECTION. 136E.9 COOPERATION OF OTHER  
5 14 AGENCIES.

5 15 All state, district, county, and city health or welfare  
5 16 agencies shall cooperate and participate in the administration

5 17 of this chapter.

5 18 Sec. 11. Chapter 136A, Code 2003, is repealed.

5 19 Sec. 12. CODE EDITOR DIRECTIVE.

5 20 1. The Code editor may transfer chapter 136E to chapter  
5 21 136A.

5 22 2. The Code editor is directed to strike the words "birth  
5 23 defects institute" and insert the words "center for congenital  
5 24 and inherited disorders" where the words appear in section  
5 25 144.13A.

5 26 3. The Code editor shall correct any references to the  
5 27 center for congenital and inherited disorders as the successor  
5 28 to the birth defects institute, including grammatical  
5 29 constructions, anywhere else in the Code, in any bills  
5 30 awaiting codification, and in any bills enacted by the  
5 31 Eightieth General Assembly, 2004 Regular Session.

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CHRISTOPHER C. RANTS  
6 1 Speaker of the House

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JEFFREY M. LAMBERTI  
6 6 President of the Senate

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6 8 I hereby certify that this bill originated in the House and  
6 9 is known as House File 2362, Eightieth General Assembly.

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MARGARET THOMSON  
6 14 Chief Clerk of the House

6 15 Approved \_\_\_\_\_, 2004

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THOMAS J. VILSACK

6 20 Governor