



THOMAS J. VILSACK
GOVERNOR

OFFICE OF THE GOVERNOR

SALLY J. PEDERSON
LT. GOVERNOR

April 2, 2004

The Honorable Chester Culver
Secretary of State
State Capitol Building
LOCAL

Dear Mr. Secretary:

I hereby transmit:

House File 2362, an Act relating to the duties of the birth defects institute by providing for a work group to study stillbirths and renaming the institute.

The above House File is hereby approved this date.

Sincerely,

A handwritten signature in black ink that reads "Thomas J. Vilsack".

Thomas J. Vilsack
Governor

TJV:jmc

cc: Secretary of the Senate
Chief Clerk of the House





HOUSE FILE 2362

AN ACT

RELATING TO THE DUTIES OF THE BIRTH DEFECTS INSTITUTE BY
PROVIDING FOR A WORK GROUP TO STUDY STILLBIRTHS AND RENAMING
THE INSTITUTE.

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

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

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

2. The Iowa department of public health shall establish a work group to develop protocol and implementation guidelines for the evaluation of causes and prevention of stillbirths including environmental and maternal factors. The director of public health shall select the members of the work group, which may include representatives from the child death review team, the health care industry, the health insurance industry, and parents or other interested parties as deemed appropriate by the director. The director shall submit a report from the work group to the general assembly on or before July 15, 2005.

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

To reduce and avoid adverse health conditions of inhabitants of the state, the Iowa department of public health shall initiate, conduct, and supervise screening and health

care programs in order to detect and predict congenital or inherited disorders. The department shall assist in the translation and integration of genetic and genomic advances into public health services to improve health outcomes throughout the life span of the inhabitants of the state.

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

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

1. "Attending health care provider" means a licensed physician, nurse practitioner, certified nurse midwife, or physician assistant.
2. "Congenital disorder" means an abnormality existing prior to or at birth, including a stillbirth, that adversely affects the health and development of a fetus, newborn, child, or adult, including a structural malformation or a genetic, chromosomal, inherited, or biochemical disorder.
3. "Department" means the Iowa department of public health.
4. "Disorder" means a congenital or inherited disorder.
5. "Genetics" means the study of inheritance and how genes contribute to health conditions and the potential for disease.
6. "Genomics" mean the functions and interactions of all human genes and their variation within human populations, including their interaction with environmental factors, and their contribution to health.
7. "Inherited disorder" means a condition caused by an abnormal change in a gene or genes passed from a parent or parents to their child. Onset of the disorder may be prior to or at birth, during childhood, or in adulthood.
8. "Stillbirth" means an unintended fetal death occurring after a gestation period of twenty completed weeks, or an unintended fetal death of a fetus with a weight of three hundred fifty or more grams.

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

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

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

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

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

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

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

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

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

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

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

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

The center may initiate, conduct, and supervise genetic health services for the inhabitants of the state, including the provision of regional genetic consultation clinics,

comprehensive neuromuscular health care outreach clinics, and other outreach services and clinics as established by rule.

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

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

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

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

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

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

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

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

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

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

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

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

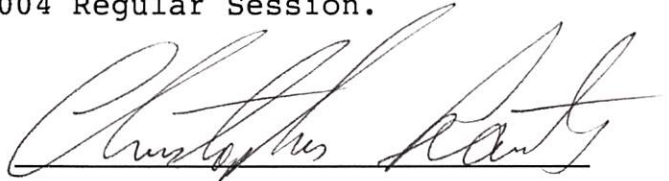
Sec. 11. Chapter 136A, Code 2003, is repealed.

Sec. 12. CODE EDITOR DIRECTIVE.

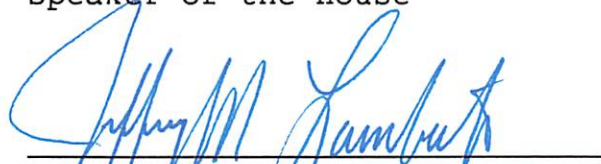
1. The Code editor may transfer chapter 136E to chapter 136A.

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

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



CHRISTOPHER C. RANTS
Speaker of the House



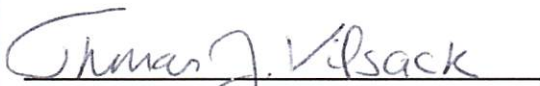
JEFFREY M. LAMBERTI
President of the Senate

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



MARGARET THOMSON
Chief Clerk of the House

Approved April 2, 2004



THOMAS J. VILSACK
Governor