A BILL FOR

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:

1.  Section 1. LEGISLATIVE INTENT AND PURPOSE == STILLBIRTHS

   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.

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.

3.  New Section. 136E.2 DEFINITIONS.

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

   1. "Attending health care provider" means a licensed
134 physician, nurse practitioner, certified nurse midwife, or
135 physician assistant.
136 2. "Congenital disorder" means an abnormality existing
137 prior to or at birth, including a stillbirth, that adversely
138 affects the health and development of a fetus, newborn, child,
139 or adult, including a structural malformation or a genetic,
140 chromosomal, inherited, or biochemical disorder.
141 3. "Department" means the Iowa department of public
142 health.
143 4. "Disorder" means a congenital or inherited disorder.
144 5. "Genetics" means the study of inheritance and how genes
145 contribute to health conditions and the potential for disease.
146 6. "Genomics" mean the functions and interactions of all
147 human genes and their variation within human populations,
148 including their interaction with environmental factors, and
149 their contribution to health.
150 7. "Inherited disorder" means a condition caused by an
151 abnormal change in a gene or genes passed from a parent or
152 parents to their child. Onset of the disorder may be prior to
153 or at birth, during childhood, or in adulthood.
154 8. "Stillbirth" means an unintended fetal death occurring
155 after a gestation period of twenty completed weeks, or an
156 unintended fetal death of a fetus with a weight of three
157 hundred fifty or more grams.
158 Sec. 4. NEW SECTION. 136E.3 ESTABLISHMENT OF CENTER FOR
159 CONGENITAL AND INHERITED DISORDERS == DUTIES.
160 A center for congenital and inherited disorders is
161 established within the department. The center shall do all of
162 the following:
163 1. Initiate, conduct, and supervise statewide screening
164 programs for congenital and inherited disorders amenable to
165 population screening.
166 2. Initiate, conduct, and supervise statewide health care
167 programs to aid in the early detection, treatment, prevention,
168 education, and provision of supportive care related to
169 congenital and inherited disorders.
170 3. Develop specifications for and designate a central
171 laboratory in which tests conducted pursuant to the screening
172 programs provided for in subsection 1 will be performed.
173 4. Gather, evaluate, and maintain information related to
174 causes, severity, prevention, and methods of treatment for
175 congenital and inherited disorders in conjunction with a
176 central registry, screening programs, genetic health care
177 programs, and ongoing scientific investigations and surveys.
178 5. Perform surveillance and monitoring of congenital and
179 inherited disorders to determine the occurrence and trends of
180 the disorders, to conduct thorough and complete
181 epidemiological surveys, to assist in the planning for and
182 provision of services to children with congenital and
183 inherited disorders and their families, and to identify
184 environmental and genetic risk factors for congenital and
185 inherited disorders.
186 6. Provide information related to severity, causes,
187 prevention, and methods of treatment for congenital and
188 inherited disorders to the public, medical and scientific
189 communities, and health science disciplines.
190 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.

EXPLANATION

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

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

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

The bill provides for confidentiality of identifiable information collected, used, or maintained by the center or department and provides the center authority to adopt rules. The Code editor is directed to make all necessary changes to existing provisions of the Code and prospective enactments by the general assembly to codify the new Code chapter.

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