

## CHAPTER 136A

### CONGENITAL AND INHERITED DISORDERS

Referred to in [§135.11](#)

<p>136A.1 Purpose. 136A.2 Definitions. 136A.3 Congenital and inherited disorders — department duties. 136A.3A Process for addition of conditions to newborn screening. 136A.4 Genetic health services. 136A.5 Newborn screening.</p>	<p>136A.5A Newborn critical congenital heart disease screening. 136A.5B Cytomegalovirus public health initiative. 136A.6 Central registry. 136A.7 Confidentiality. 136A.8 Rules. 136A.9 Cooperation of other agencies.</p>
--	--

#### **136A.1 Purpose.**

To reduce and avoid adverse health conditions of inhabitants of the state, the department 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.

[2004 Acts, ch 1031, §2, 12](#); [2023 Acts, ch 19, §198](#)

#### **136A.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. “*Council*” means the council on health and human services.
4. “*Department*” means the department of health and human services.
5. “*Disorder*” means a congenital or inherited disorder.
6. “*Genetics*” means the study of inheritance and how genes contribute to health conditions and the potential for disease.
7. “*Genomics*” means 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.
8. “*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.
9. “*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.

[2004 Acts, ch 1031, §3, 12](#); [2022 Acts, ch 1023, §1](#); [2023 Acts, ch 19, §199](#); [2024 Acts, ch 1170, §432](#)

Referred to in [§144.31A](#)

#### **136A.3 Congenital and inherited disorders — department duties.**

The department 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.

[2004 Acts, ch 1031, §4, 12; 2023 Acts, ch 19, §200](#)

Referred to in [§136A.5B](#)

### **136A.3A Process for addition of conditions to newborn screening.**

1. The council shall assist the department in the development of programs that ensure the availability and access to quality genetic and genomic health care services for all Iowans.

2. The council shall assist the department in designating the conditions to be included in the newborn screening and in regularly evaluating the effectiveness and appropriateness of the newborn screening.

3. *a.* Beginning July 1, 2022, the council shall ensure that all conditions included in the federal recommended uniform screening panel as of January 1, 2022, are included in the newborn screening.

*b.* Within twelve months of the addition of a new condition to the federal recommended uniform screening panel, the council shall consider and make a recommendation to the department regarding inclusion of the new condition in the newborn screening, including the current newborn screening capacity to screen for the new condition and the resources necessary to screen for the new condition going forward. If the council recommends inclusion of a new condition, the department shall include the new condition in the newborn screening within eighteen months of receipt of the recommendation.

4. The department shall submit a status report to the general assembly, annually, by December 31, regarding all of the following:

*a.* The current conditions included in the newborn screening.

*b.* Any new conditions currently under consideration or recommended by the council for inclusion in the newborn screening.

*c.* Any new conditions considered but not recommended by the council in the prior twelve-month period and the reason for not recommending any such conditions.

*d.* Any departmental request for additional program capacity or resources necessitated by the inclusion of a recommended new condition in the newborn screening.

*e.* Any delay and the reason for the delay by the council in complying with the specified twelve-month time frame in considering or recommending the inclusion of a new condition in the newborn screening to the department.

*f.* Any delay and the reason for the delay by the department in complying with the specified eighteen-month time frame in including a new condition in the newborn screening following receipt of a recommendation from the council recommending the inclusion of such condition.

5. The state hygienic laboratory shall establish the newborn screening fee schedule in

a manner sufficient to support the newborn screening system of care including laboratory screening costs, short-term and long-term follow-up program costs, the newborn screening developmental fund, and the cost of the department's newborn screening data system.

2022 Acts, ch 1023, §2; 2023 Acts, ch 19, §201; 2024 Acts, ch 1043, §56; 2024 Acts, ch 1170, §433

#### **136A.4 Genetic health services.**

The department 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.

2004 Acts, ch 1031, §5, 12; 2023 Acts, ch 19, §202

#### **136A.5 Newborn 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 a 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.

2004 Acts, ch 1031, §6, 12; 2005 Acts, ch 19, §33; 2022 Acts, ch 1023, §3

Referred to in §136A.5A, 1481.4

#### **136A.5A Newborn critical congenital heart disease screening.**

1. Each newborn born in this state shall receive a critical congenital heart disease screening by pulse oximetry or other means as determined by rule, in conjunction with the newborn screening required pursuant to [section 136A.5](#).

2. An attending health care provider shall ensure that every newborn under the provider's care receives the critical congenital heart disease screening.

3. [This section](#) does not apply if a 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.

4. Notwithstanding any provision to the contrary, the results of each newborn's critical congenital heart disease screening shall only be reported in a manner consistent with the reporting of the results of newborn screenings pursuant to [section 136A.5](#) if funding is available for implementation of the reporting requirement.

5. [This section](#) shall be administered in accordance with rules adopted pursuant to [section 136A.8](#).

2013 Acts, ch 140, §91; 2022 Acts, ch 1023, §4

Referred to in §1481.4

#### **136A.5B Cytomegalovirus public health initiative.**

1. In accordance with the duties prescribed in [section 136A.3](#), the department shall collaborate with state and local health agencies and other public and private organizations to develop and publish or approve and publish informational materials to educate and raise awareness of cytomegalovirus and congenital cytomegalovirus among women who may become pregnant, expectant parents, parents of infants, attending health care providers, and others, as appropriate. The materials shall include information regarding all of the following:

- a. The incidence of cytomegalovirus and congenital cytomegalovirus.
- b. The transmission of cytomegalovirus to a pregnant woman or a woman who may become pregnant.
- c. Birth defects caused by congenital cytomegalovirus.
- d. Methods of diagnosing congenital cytomegalovirus.

e. Available preventive measures to avoid cytomegalovirus infection by women who are pregnant or who may become pregnant.

f. Early interventions, treatment, and services available for children diagnosed with congenital cytomegalovirus.

2. An attending health care provider shall provide to a pregnant woman during the first trimester of the pregnancy the informational materials published under [this section](#). The department shall make the informational materials available to attending health care providers upon request.

3. The department shall publish the informational materials on its internet site and shall specifically make the informational materials available electronically to child care facilities and child care homes as defined in [section 237A.1](#), school nurses, hospitals, attending health care providers, and other health care providers offering care to pregnant women and infants.

[2017 Acts, ch 77, §1](#); [2018 Acts, ch 1026, §51](#); [2023 Acts, ch 19, §203, 204](#)

### **136A.6 Central registry.**

The department 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.

[2004 Acts, ch 1031, §7, 12](#); [2023 Acts, ch 19, §205](#)

Referred to in [§144.13A](#)

### **136A.7 Confidentiality.**

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](#).

[2004 Acts, ch 1031, §8, 12](#); [2023 Acts, ch 19, §206](#)

### **136A.8 Rules.**

The department shall adopt rules pursuant to [chapter 17A](#) to administer [this chapter](#).

[2004 Acts, ch 1031, §9, 12](#); [2023 Acts, ch 19, §207](#)

Referred to in [§136A.5A](#)

### **136A.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](#).

[2004 Acts, ch 1031, §10, 12](#)