

## CHAPTER 1023

### CONGENITAL AND INHERITED DISORDERS — SCREENING OF NEWBORNS

S.F. 2345

AN ACT relating to the newborn screening.

Be It Enacted by the General Assembly of the State of Iowa:

Section 1. [Section 136A.2](#), Code 2022, is amended by adding the following new subsection:

**NEW SUBSECTION. 1A.** “*Congenital and inherited disorders advisory committee*” or “*advisory committee*” means the congenital and inherited disorders advisory committee created in [this chapter](#).

Sec. 2. **NEW SECTION. 136A.3A Congenital and inherited disorders advisory committee established — process for addition of conditions to newborn screening.**

1. A congenital and inherited disorders advisory committee is established to assist the center for congenital and inherited disorders and 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 members of the advisory committee shall be appointed by the director and shall include persons with relevant expertise and interest including parent representatives.

3. The advisory committee shall assist the center for congenital and inherited disorders and 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.

4. *a.* Beginning July 1, 2022, the advisory committee 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 advisory committee 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 advisory committee 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.

5. 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 advisory committee for inclusion in the newborn screening.

*c.* Any new conditions considered but not recommended by the advisory committee 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 advisory committee 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 advisory committee recommending the inclusion of such condition.

6. 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.

Sec. 3. [Section 136A.5](#), Code 2022, is amended to read as follows:

**136A.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 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.

Sec. 4. [Section 136A.5A, subsections 1 and 4](#), Code 2022, are amended to read as follows:

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 ~~metabolic newborn~~ screening required pursuant to [section 136A.5](#).

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 ~~metabolic newborn~~ screenings pursuant to [section 136A.5](#) if funding is available for implementation of the reporting requirement.

Approved April 21, 2022