

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 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 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.

[2022 Acts, ch 1023, §2](#); [2023 Acts, ch 19, §201](#)

Subsections 1 and 3 amended