

House Study Bill 690 - Introduced

HOUSE FILE _____

BY (PROPOSED COMMITTEE ON
HUMAN RESOURCES BILL BY
CHAIRPERSON MEYER)

A BILL FOR

1 An Act relating to the newborn screening.

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

1 Section 1. Section 136A.2, Code 2022, is amended by adding
2 the following new subsection:

3 NEW SUBSECTION. 1A. *“Congenital and inherited disorders*
4 *advisory committee”* or *“advisory committee”* means the congenital
5 and inherited disorders advisory committee created in this
6 chapter.

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

10 1. A congenital and inherited disorders advisory committee
11 is established to assist the center for congenital and
12 inherited disorders and the department in the development of
13 programs that ensure the availability and access to quality
14 genetic and genomic health care services for all Iowans.

15 2. The members of the advisory committee shall be appointed
16 by the director and shall include persons with relevant
17 expertise and interest including parent representatives.

18 3. The advisory committee shall assist the center for
19 congenital and inherited disorders and the department in
20 designating the conditions to be included in the newborn
21 screening and in regularly evaluating the effectiveness and
22 appropriateness of the newborn screening.

23 4. Within twelve months of the addition of a new condition
24 to the federal recommended uniform screening panel, the
25 advisory committee shall consider and make a recommendation
26 to the department regarding inclusion of the new condition in
27 the newborn screening, including the current newborn screening
28 capacity to screen for the new condition and the resources
29 necessary to screen for the new condition going forward.

30 If the advisory committee recommends inclusion of a new
31 condition, the department shall include the new condition in
32 the newborn screening within eighteen months of receipt of the
33 recommendation, subject to the provision of necessary newborn
34 screening capacity and resources.

35 5. The department shall submit a status report to the

1 general assembly, annually, by December 31, regarding all of
2 the following:

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

4 *b.* Any new conditions currently under consideration or
5 recommended by the advisory committee for inclusion in the
6 newborn screening.

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

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

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

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

22 Sec. 3. Section 136A.5, Code 2022, is amended to read as
23 follows:

24 **136A.5 Newborn ~~metabolic~~ screening.**

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

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

32 3. **This section** does not apply if a parent objects to
33 the screening. If a parent objects to the screening of a
34 newborn, the attending health care provider shall document the
35 refusal in the newborn's medical record and shall obtain a

1 written refusal from the parent and report the refusal to the
2 department as provided by rule of the department.

3 Sec. 4. Section 136A.5A, subsections 1 and 4, Code 2022, are
4 amended to read as follows:

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

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

15 EXPLANATION

16 The inclusion of this explanation does not constitute agreement with
17 the explanation's substance by the members of the general assembly.

18 This bill relates to newborn screenings.

19 The bill establishes, in Code, the congenital and inherited
20 disorders advisory committee (advisory committee), which
21 currently is established in administrative rules. The bill
22 provides, as is provided in administrative rules, that the
23 advisory committee is established to assist the center for
24 congenital and inherited disorders (center) and the department
25 of public health (DPH) in matters relating to genetic
26 and genomic health care services for all Iowans, that the
27 members of the advisory committee shall be appointed by the
28 director of public health, that the members shall include
29 persons with relevant expertise and interest including parent
30 representatives, and that one of the duties of the advisory
31 committee is to assist the center and DPH in designating the
32 conditions to be included in the newborn screening and in
33 regularly evaluating the effectiveness and appropriateness of
34 the newborn screening.

35 The bill specifically requires that within 12 months of the

1 addition of a new condition to the federal recommended uniform
2 screening panel, the advisory committee shall consider and
3 make a recommendation to DPH regarding inclusion of the new
4 condition in the newborn screening, including current newborn
5 screening capacity to screen for the new condition and the
6 resources necessary to screen for the new condition going
7 forward. If the advisory committee recommends inclusion of
8 a new condition, DPH shall ensure that the new condition is
9 included in the newborn screening within 18 months of receipt
10 of the recommendation, subject to the provision of necessary
11 newborn screening capacity and resources.

12 The bill requires DPH to submit an annual report to the
13 general assembly by December 31, regarding the current
14 conditions included in the newborn screening, any new
15 conditions currently under consideration or recommended by the
16 advisory committee for inclusion in the newborn screening, any
17 new conditions considered but not recommended by the advisory
18 committee in the prior 12-month period and the reason for not
19 recommending any such conditions, any departmental request for
20 additional newborn screening program capacity or resources
21 necessitated by the inclusion of a recommended new condition
22 in the newborn screening, and any delay and the reason for
23 the delay by the advisory committee or DPH in complying with
24 the specified time frames for considering and recommending or
25 adding a new condition to the newborn screening.

26 The bill also changes references to "newborn metabolic
27 screening" or "metabolic newborn screening" to "newborn
28 screening".