

Senate File 341 - Introduced

SENATE FILE 341

BY LYKAM

A BILL FOR

1 An Act relating to expansion of the newborn metabolic screening
2 to include lysosomal storage disorders.

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

1 Section 1. NEW SECTION. 136A.5B Newborn metabolic screening
2 — lysosomal storage disorders.

3 1. The department shall adopt rules pursuant to section
4 136A.8 to expand the newborn metabolic screening required under
5 section 136A.5 to include screening for lysosomal storage
6 disorders, including but not limited to all of the following:

- 7 a. Krabbe disease.
- 8 b. Pompe disease.
- 9 c. Gaucher disease.
- 10 d. Niemann-Pick disease.
- 11 e. Fabry disease.

12 2. An attending health care provider shall ensure that
13 every newborn under the provider's care receives the newborn
14 screening that includes screening for lysosomal storage
15 disorders in accordance with rules adopted by the department.

16 3. a. In accordance with the duties prescribed in section
17 136A.3, the center for congenital and inherited disorders shall
18 collaborate with state and local health agencies and other
19 public and private organizations to develop and publish or
20 approve and publish informational materials to educate and
21 raise awareness of lysosomal storage disorders among women who
22 may become pregnant, expectant parents, parents of newborns,
23 attending health care providers, and others, as appropriate.

24 b. An attending health care provider shall provide to a
25 pregnant woman during the first trimester of the pregnancy,
26 the informational materials published under this subsection.
27 The center for congenital and inherited disorders shall make
28 the informational materials available to attending health care
29 providers upon request.

30 c. The department shall publish the informational materials
31 on its internet site.

32 4. 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.

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EXPLANATION

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The inclusion of this explanation does not constitute agreement with

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the explanation's substance by the members of the general assembly.

6 This bill directs the department of public health (DPH)
7 to adopt rules to expand the newborn metabolic screening to
8 include screening for lysosomal storage disorders, including
9 but not limited to five such disorders as specified.
10 The bill requires an attending health care provider to
11 ensure that every newborn under the provider's care receives
12 the newborn screening that includes screening for lysosomal
13 storage disorders; directs the center for congenital and
14 inherited disorders to collaborate with state and local health
15 agencies and other public and private organizations to develop
16 and publish or approve and publish informational materials to
17 educate and raise awareness of lysosomal storage disorders
18 among women who may become pregnant, expectant parents, parents
19 of newborns, attending health care providers, and others,
20 as appropriate; requires an attending health care provider
21 to provide to a pregnant woman during the first trimester
22 of the pregnancy, the informational materials published;
23 requires the center for congenital and inherited disorders
24 to make the informational materials available to attending
25 health care providers upon request; and requires DPH to
26 publish the informational materials on its internet site. The
27 requirement for screening does not apply if a parent objects
28 to the screening. If a parent objects to the screening of
29 a newborn, the attending health care provider shall document
30 the refusal in the newborn's medical record and shall obtain a
31 written refusal from the parent and report the refusal to the
32 department.