

REFERENCE TITLE: newborn screening; Duchenne muscular dystrophy

State of Arizona
Senate
Fifty-sixth Legislature
Second Regular Session
2024

SB 1020

Introduced by
Senators Shope; Marsh; Representatives Cook, Pawlik, Terech

AN ACT

AMENDING SECTION 36-694, ARIZONA REVISED STATUTES; RELATING TO THE NEWBORN SCREENING PROGRAM.

(TEXT OF BILL BEGINS ON NEXT PAGE)

1 Be it enacted by the Legislature of the State of Arizona:

2 Section 1. Section 36-694, Arizona Revised Statutes, is amended to
3 read:

4 36-694. Report of blood tests; newborn screening program;
5 committee; fee; definitions

6 A. When a birth or stillbirth is reported, the attending physician
7 or other person required to report the birth shall state on the
8 certificate whether a blood test for syphilis was made on a specimen of
9 blood taken from the woman who bore the child or from the umbilical cord
10 at delivery, as required by section 36-693, and the approximate date when
11 the specimen was taken.

12 B. When a birth is reported, the attending physician or person who
13 is required to report the birth shall order or cause to be ordered tests
14 for certain congenital disorders, including hearing disorders. The
15 results of tests for these disorders must be reported to the department of
16 health services. The department of health services shall specify in rule
17 the disorders, the process for collecting and submitting specimens and the
18 reporting requirements for test results.

19 C. When a hearing test is performed on a newborn, the initial
20 hearing test results and any subsequent hearing test results must be
21 reported to the department of health services as prescribed by department
22 rules.

23 D. The director of the department of health services shall
24 establish a newborn screening program within the department to ensure that
25 the testing for congenital disorders and the reporting of hearing test
26 results required by this section are conducted in an effective and
27 efficient manner. The newborn screening program shall include all
28 congenital disorders that are included on the recommended uniform
29 screening panel adopted by the secretary of the United States department
30 of health and human services for both core and secondary conditions.
31 Beginning January 1, 2022, CONGENITAL disorders that are added to the core
32 and secondary conditions list of the recommended uniform screening panel
33 shall be added to this state's newborn screening panel within two years
34 after their addition to the recommended uniform screening panel. The
35 newborn screening program shall include an education program for the
36 general public, the medical community, parents and professional groups.
37 The director shall designate the state laboratory as the only testing
38 facility for the program, except that the director may designate other
39 laboratory testing facilities for conditions or tests added to the newborn
40 screening program on or after July 24, 2014. If the director designates
41 another laboratory testing facility for any condition or test, the
42 director shall require the facility to follow all of the privacy and
43 sample destruction time frames that are required of the state laboratory.

1 E. ON OR BEFORE DECEMBER 31, 2024, IN ADDITION TO THE CONGENITAL
2 DISORDERS ADDED TO THIS STATE'S NEWBORN SCREENING PANEL PURSUANT TO
3 SUBSECTION D OF THIS SECTION, THE DEPARTMENT SHALL ADD DUCHENNE MUSCULAR
4 DYSTROPHY TO THIS STATE'S NEWBORN SCREENING PANEL.

5 ~~F.~~ F. The newborn screening program shall establish and maintain a
6 central database of newborns and infants who are tested for hearing loss
7 and congenital disorders that includes information required in rule. Test
8 results are confidential subject to the disclosure provisions of sections
9 12-2801 and 12-2802.

10 ~~F.~~ G. If tests conducted pursuant to this section indicate that a
11 newborn or infant may have a hearing loss or a congenital disorder, the
12 screening program shall provide follow-up services to encourage the
13 child's family to access evaluation services, specialty care and early
14 intervention services.

15 ~~G.~~ H. The director shall establish a committee to provide
16 recommendations and advice to the department on at least an annual basis
17 regarding newborn screening best practices and emerging trends.

18 ~~H.~~ I. The director may establish by rule a fee that the department
19 may collect for operating the newborn screening program, including
20 contracting for the testing pursuant to this section. The director shall
21 present any change to the fee for the newborn screening program to the
22 joint legislative budget committee for review.

23 ~~I.~~ J. Not later than sixty days after the department adjusts the
24 newborn screening program fee established pursuant to subsection ~~H.~~ I of
25 this section:

26 1. Each health insurer that is subject to title 20 shall update its
27 hospital rates that include newborn screening to reflect the increase.

28 2. For the Arizona health care cost containment system and
29 contractors acting pursuant to chapter 29, article 1 of this title that
30 are not subject to title 20, the Arizona health care cost containment
31 system shall update its hospital rates that include newborn screening to
32 reflect the increase.

33 ~~J.~~ K. For the purposes of this section:

34 1. "Infant" means a child who is twenty-nine days of age to two
35 years of age.

36 2. "Newborn" means a child who is not more than twenty-eight days
37 of age.