

Senate Engrossed

newborn screening; Duchenne muscular dystrophy

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

# SENATE BILL 1020

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. IN ADDITION TO THE CONGENITAL DISORDERS ADDED TO THIS STATE'S  
2 NEWBORN SCREENING PANEL PURSUANT TO SUBSECTION D OF THIS SECTION, THE  
3 DEPARTMENT SHALL ADD DUCHENNE MUSCULAR DYSTROPHY TO THIS STATE'S NEWBORN  
4 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.

38 Sec. 2. Effective date; notification

39 A. Section 36-694, Arizona Revised Statutes, as amended by this  
40 act, is effective the earlier of either of the following:

41 1. October 1, 2026.

42 2. Two years from the date Duchenne muscular dystrophy is added to  
43 the recommended uniform screening panel adopted by the secretary of the  
44 United States department of health and human services.

1           B. The director of the department of health services shall notify  
2 the director of the Arizona legislative council in writing within ten days  
3 after the date that Duchenne muscular dystrophy is added to the  
4 recommended uniform screening panel adopted by the secretary of the United  
5 States department of health and human services.