

By Senator Garcia

38-00603-15

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1 A bill to be entitled
2 An act relating to newborn adrenoleukodystrophy
3 screening; creating s. 383.147, F.S.; providing
4 definitions; directing the Department of Health to
5 establish requirements for newborn
6 adrenoleukodystrophy screening; providing certain
7 insurance and managed care coverage; providing
8 adrenoleukodystrophy screening as a covered benefit;
9 providing an exemption; providing for documentation of
10 objections to screening by the parent or legal
11 guardian; providing an effective date.

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13 Be It Enacted by the Legislature of the State of Florida:

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15 Section 1. Section 383.147, Florida Statutes, is created to
16 read:

17 383.147 Newborn adrenoleukodystrophy screening.-

18 (1) DEFINITIONS.-As used in this section, the term:

19 (a) "Adrenoleukodystrophy screening" means a test
20 administered to newborns which identifies the presence of
21 adrenoleukodystrophy, a disease of the central nervous system
22 that is inherited as an X-linked recessive trait and is
23 characterized by blindness, deafness, tonic spasms, and mental
24 deterioration.

25 (b) "Agency" means the Agency for Health Care
26 Administration.

27 (c) "Department" means the Department of Health.

28 (d) "Newborn" means an infant ranging in age from birth
29 through 29 days.

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30 (2) SCREENING REQUIREMENTS.—The department shall adopt
31 rules requiring a newborn to be screened for
32 adrenoleukodystrophy. Notwithstanding any provision of law, a
33 licensed hospital, birth center, or attending health care
34 provider may release, directly or through the Children’s Medical
35 Services program, the results of an adrenoleukodystrophy
36 screening to the newborn’s primary care physician.

37 (a) A licensed hospital that provides maternity and newborn
38 care services shall provide an adrenoleukodystrophy screening
39 for each newborn within 24 hours after birth or admittance to
40 the hospital and before he or she is discharged.

41 (b) A licensed birth center that provides maternity and
42 newborn care services shall refer each newborn to a physician
43 licensed under chapter 458 or chapter 459 or to a hospital for
44 adrenoleukodystrophy screening within 24 hours after birth or
45 admittance to the birth center and before he or she is
46 discharged. Written documentation of the referral must be placed
47 in the newborn’s medical chart.

48 (c) For a home birth, the health care provider in
49 attendance must refer the newborn to a physician licensed under
50 chapter 458 or chapter 459 or to a hospital for an
51 adrenoleukodystrophy screening within 24 hours after the birth
52 of the newborn.

53 (d) Each hospital shall designate a lead physician who is
54 responsible for programmatic oversight of newborn
55 adrenoleukodystrophy screenings. Each birth center shall
56 designate a licensed health care provider who is responsible for
57 programmatic oversight of referrals for and completion of
58 newborn adrenoleukodystrophy screenings.

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59 (3) INSURANCE COVERAGE.—The initial procedure for newborn
60 adrenoleukodystrophy screening is a covered benefit,
61 reimbursable under Medicaid as an expense compensated
62 supplemental to the per diem rate for Medicaid patients enrolled
63 in MediPass or Medicaid patients covered by a fee-for-service
64 program. For Medicaid patients enrolled in health maintenance
65 organizations, providers shall be reimbursed directly by the
66 Medicaid Program Office at the Medicaid rate.
67 Adrenoleukodystrophy screening may not be considered a covered
68 service for the purposes of establishing the payment rate for
69 Medicaid health maintenance organizations. All health insurance
70 policies and health maintenance organizations as provided under
71 ss. 627.6416, 627.6579, and 641.31(30), except for supplemental
72 policies that provide coverage only for specific diseases or
73 hospital indemnity, or as a Medicare supplement, or to the
74 supplemental polices, shall compensate providers for the covered
75 benefit at the contracted rate. Nonhospital-based providers may
76 bill Medicaid for the professional and technical component of
77 each procedure code.

78 (4) OBJECTIONS OF PARENT OR GUARDIAN.—If the parent or
79 legal guardian of a newborn objects to the adrenoleukodystrophy
80 screening, the screening may not be completed. In such case, the
81 licensed hospital, licensed birth center, or, in the case of a
82 home birth, the physician, midwife, or other person attending
83 the newborn, shall maintain a record that the screening has not
84 been performed and attach a written objection that is signed by
85 the parent or legal guardian.

86 Section 2. This act shall take effect July 1, 2015.