

1 A bill to be entitled
 2 An act relating to newborn adrenoleukodystrophy
 3 screening; creating s. 383.146, F.S.; providing
 4 definitions; directing the Department of Health to
 5 establish requirements for newborn
 6 adrenoleukodystrophy screening; providing for certain
 7 insurance and managed care coverage; providing for
 8 documentation of objections to screening by the parent
 9 or guardian; providing an effective date.

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

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13 Section 1. Section 383.146, Florida Statutes, is created
 14 to read:

15 383.146 Newborn adrenoleukodystrophy screening.—

16 (1) DEFINITIONS.—As used in this section, the term:

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

23 (b) "Agency" means the Agency for Health Care
 24 Administration.

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

26 (d) "Newborn" means an age range from birth through 29

27 days.

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

35 (a) A licensed hospital that provides maternity and
36 newborn care services shall provide an adrenoleukodystrophy
37 screening for a newborn within 24 hours after birth and before
38 discharge.

39 (b) A licensed birth center that provides maternity and
40 newborn care services shall refer a newborn to a physician
41 licensed under chapter 458 or chapter 459 or to a hospital for
42 adrenoleukodystrophy screening within 24 hours after birth and
43 before discharge. Written documentation of the referral must be
44 placed in the newborn's medical chart.

45 (c) For a home birth, the health care provider in
46 attendance must refer a newborn to a physician licensed under
47 chapter 458 or chapter 459 or to a hospital for
48 adrenoleukodystrophy screening within 24 hours after birth and
49 before discharge.

50 (d) Each hospital shall designate a lead physician
51 responsible for programmatic oversight of newborn
52 adrenoleukodystrophy screening. Each birth center shall

53 designate a licensed health care provider responsible for
54 programmatic oversight of referrals for and completion of
55 newborn adrenoleukodystrophy screening.

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

74 (4) OBJECTIONS OF PARENT OR GUARDIAN.—If the parent or
75 legal guardian of the newborn objects to the
76 adrenoleukodystrophy screening, the screening may not be
77 completed. In such case, the physician, midwife, or other person
78 who is attending the newborn shall maintain a record that the

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79 | screening has not been performed and attach a written objection
80 | that must be signed by the parent or guardian.

81 | Section 2. This act shall take effect July 1, 2014.