

1 A bill to be entitled
 2 An act relating to newborn adrenoleukodystrophy
 3 screening; creating s. 383.147, F.S.; providing a
 4 short title; providing definitions; directing the
 5 Department of Health to establish requirements for
 6 newborn adrenoleukodystrophy screening; providing for
 7 certain insurance and managed care coverage; providing
 8 for documentation of objections to screening by the
 9 parent 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 383.147, Florida Statutes, is created
 14 to read:

15 383.147 Newborn adrenoleukodystrophy screening.—

16 (1) SHORT TITLE.—This section may be cited as "Gabriel's
 17 Law."

18 (2) DEFINITIONS.—As used in this section, the term:

19 (a) "Adrenoleukodystrophy screening" means a test
 20 administered to newborns that 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 age range from birth through 29
 29 days.

30 (3) SCREENING REQUIREMENTS.—The department shall adopt
 31 rules requiring a newborn born in this state 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 the adrenoleukodystrophy
 36 screening to the newborn's primary care physician.

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

41 (b) A licensed birth center that provides maternity and
 42 newborn care services shall refer a 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 and
 45 before discharge. Written documentation of the referral must be
 46 placed in the newborn's medical chart.

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

51 (d) Each hospital shall designate a lead physician
 52 responsible for programmatic oversight of newborn

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

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

75 (5) OBJECTIONS OF PARENT OR GUARDIAN.—If the parent or
76 legal guardian of the newborn objects to the
77 adrenoleukodystrophy screening, the screening may not be
78 completed. In such case, the physician, midwife, or other person

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79 who is attending the newborn shall maintain a record that the
80 screening has not been performed and attach a written objection
81 that must be signed by the parent or guardian.

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