

**The Florida Senate**  
**BILL ANALYSIS AND FISCAL IMPACT STATEMENT**

(This document is based on the provisions contained in the legislation as of the latest date listed below.)

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Prepared By: The Professional Staff of the Appropriations Committee on Health and Human Services

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BILL: SB 1574

INTRODUCER: Senators Bracy Davis and Sharief

SUBJECT: Newborn Screenings

DATE: February 24, 2026

REVISED: \_\_\_\_\_

	ANALYST	STAFF DIRECTOR	REFERENCE	ACTION
1.	<u>Looke</u>	<u>Brown</u>	<u>HP</u>	<b>Favorable</b>
2.	<u>Gerbrandt</u>	<u>McKnight</u>	<u>AHS</u>	<b>Pre-meeting</b>
3.	_____	_____	<u>FP</u>	_____

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**I. Summary:**

SB 1574 creates “Mattie’s Law,” and requires the Department of Health (DOH) to:

- Require each newborn be screened for biliary atresia (BA) using the blood specimen collected for newborn screenings.
- Implement a statewide public health education campaign to increase public awareness and understanding of BA and its associated risks.
- Consult with the Genetics and Newborn Screening Advisory Council before adopting rules regarding screening methods, follow-up procedures, and the inclusion of additional conditions in the screening program.

The bill also creates s. 395.3043, F.S., to require hospitals that provide birthing services to screen newborns for BA pursuant to the new requirement.

The bill has a significant, negative fiscal impact on state expenditures. **See Section V., Fiscal Impact Statement.**

The bill takes effect July 1, 2026.

**II. Present Situation:**

**Biliary Atresia (BA)**

BA is a serious condition that is estimated to occur in one out of every 12,000 babies in the United States and in which a baby’s bile ducts are blocked and cannot send bile from their liver to their small intestine. Bile is a substance a baby’s liver produces that carries waste products to their intestines. Bile also helps a baby’s intestines digest and absorb vital nutrients. BA affects babies in their first few months of life and can quickly lead to severe liver damage without prompt treatment.

A slowdown or stalling of bile flow (cholestasis) affects a baby's liver and all the organs and tissues surrounding it. Bile clogs up in a baby's liver and causes scarring that can prevent the baby's liver from working normally. Also, an afflicted baby's intestines cannot receive the bile needed to break down nutrients and support growth.<sup>1</sup>

BA has a well-established treatment which can delay or even avoid the need for liver transplant. This treatment, Kasai portoenterostomy (KP), directly connects the intestines to the liver to restore bile flow. A critical factor predicting KP outcomes is the time at which the operation is performed. KPs performed before 30 to 45 days of life have the greatest chances of delaying or avoiding liver transplant. Unfortunately, in the United States, without screening, the average age at the time of KP is after 60 days of life and there have been no recent improvements.<sup>2</sup>

One screening strategy for BA is a two-stage screening that looks at serum bilirubin measurements. A study on four Houston, Texas, area hospitals over a 15-month period looked at bilirubin measurements in 11,636 infants and considered newborns to be positive if they had a direct or conjugated bilirubin concentration higher than the 95<sup>th</sup> percentile. In the second stage, an infant was considered to be positive if he or she had rising concentrations of bilirubin at or before the first well-child visit. Of the 11 infants that tested positive in both stages, two had BA. Of the two infants with BA, the KP was unable to be performed on one of them due to severe congenital heart disease. After the KP procedure, the other infant's bilirubin concentration normalized within three months and the patient survived, transplant-free past two years of age.<sup>3</sup>

### **Florida's Newborn Screening Program**

Established in s. 383.14, F.S., Florida's Newborn Screening Program requires the Department of Health (DOH) to promote the screening of all newborns born in Florida for metabolic, hereditary, and congenital disorders known to result in significant impairment of health or intellect, as screening programs accepted by current medical practice become available and practical in the judgment of the DOH. The primary method of screening is a blood sample which is collected on a specimen card and submitted to the State Public Health Laboratory for testing.<sup>4</sup> The State Public Health Laboratory is required to send a written report with the results of the newborn screening to the submitting entity within five calendar days after receipt of the specimen.<sup>5</sup> Currently, the screening program screens for 37 core conditions and may detect an additional 23 secondary conditions.<sup>6</sup>

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<sup>1</sup> *Biliary Atresia*, Cleveland Clinic, last updated Aug. 9, 2023, available at <https://my.clevelandclinic.org/health/diseases/21076-biliary-atresia>, (last visited Feb. 5, 2026).

<sup>2</sup> Rabbani T, Guthery SL, Himes R, Shneider BL, Harpavat S. Newborn Screening for Biliary Atresia: a Review of Current Methods. *Curr Gastroenterol Rep.* 2021 Nov 24;23(12):28. doi: 10.1007/s11894-021-00825-2. PMID: 34817690; PMCID: PMC8651301.

<sup>3</sup> Newborn Bilirubin Screening for Biliary Atresia, August 11, 2016, *N. Engl. J. Med.* 2016;375:605-606, VOL. 375 NO.6.

<sup>4</sup> Rule 64C-7.002, F.A.C.

<sup>5</sup> Rule 64C-7.005, F.A.C.

<sup>6</sup> For a full list of conditions, see <https://floridanewbornscreening.com/conditions/core-secondary-conditions/>, (last visited Feb. 5, 2026).

### III. Effect of Proposed Changes:

The bill creates “Mattie’s Law.” The bill amends s. 383.14, F.S., to require the Department of Health (DOH) to:

- Adopt rules that, beginning January 1, 2027, require each newborn be screened for biliary atresia (BA) using the blood specimen collected for newborn screenings.
- By October 1, 2026, implement a statewide public health education campaign to increase public awareness and understanding of BA and its associated risks. The campaign, at a minimum, must:
  - Educate new and expecting parents on the symptoms of BA and the importance of early diagnosis; and
  - Provide guidance to physicians, physician assistants, and nurses on strategies for identifying BA in infants and the risks of delayed treatment.
- Consult with the Genetics and Newborn Screening Advisory Council before adopting rules regarding screening methods, follow-up procedures, and the inclusion of additional conditions in the screening program.

The bill also creates s. 395.3043, F.S., to require hospitals that provide birthing services to screen newborns for BA pursuant to the new requirement.

The bill takes effect July 1, 2026.

### IV. Constitutional Issues:

#### A. Municipality/County Mandates Restrictions:

None.

#### B. Public Records/Open Meetings Issues:

None.

#### C. Trust Funds Restrictions:

None.

#### D. State Tax or Fee Increases:

None.

#### E. Other Constitutional Issues:

None.

### V. Fiscal Impact Statement:

#### A. Tax/Fee Issues:

None.

**B. Private Sector Impact:**

None.

**C. Government Sector Impact:**

- The bill has a significant negative recurring fiscal impact on the Department of Health (DOH). According to the DOH, the bill will require \$3,386,165, as follows:<sup>7</sup>

**Follow-up Activities:**

- Two Nurse Consultants – \$235,517.
- Follow-up Referral Centers Contract – \$1,585,704.
- Statewide Education Campaign – \$380,000.
- Other Expenses - \$61,962.

• **Laboratory Activities:**

- Testing Kits - \$828,000.
- Two Licensed Laboratory Staff - \$219,982.
- Technology Updates - \$75,000 nonrecurring.

**VI. Technical Deficiencies:**

None.

**VII. Related Issues:**

None.

**VIII. Statutes Affected:**

This bill substantially amends section 383.14 of the Florida Statutes.

This bill creates section 395.3043 of the Florida Statutes.

**IX. Additional Information:****A. Committee Substitute – Statement of Changes:**

(Summarizing differences between the Committee Substitute and the prior version of the bill.)

None.

**B. Amendments:**

None.

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This Senate Bill Analysis does not reflect the intent or official position of the bill's introducer or the Florida Senate.

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<sup>7</sup> Fl. Dept. of Health, *2026 Agency Bill Analysis* (SB 1574) (on file with the Seante Appropriations Committee on Health and Human Services).