

119TH CONGRESS
1ST SESSION

H. R. 5355

To direct the Secretary of Health and Human Services to carry out activities to promote screenings for liver diseases in newborns, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 15, 2025

Mr. COSTA (for himself and Ms. VAN DUYNE) introduced the following bill;
which was referred to the Committee on Energy and Commerce

A BILL

To direct the Secretary of Health and Human Services to carry out activities to promote screenings for liver diseases in newborns, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Ian Kalvinskas Pedi-
5 atric Liver Cancer Early Detection and Screening Act”.

6 **SEC. 2. FINDINGS.**

7 Congress finds that—

8 (1) the life of California teenager Ian
9 Kalvinskas—who received a liver transplant, fulfilled
10 his goal of interning on Capitol Hill, and died from

1 cancer on June 27, 2025—demonstrates the urgent
2 need for earlier detection of pediatric liver disease,
3 lifelong follow-up, and wider access to donor organs;

4 (2) pediatric primary liver tumors are among
5 the fastest-rising childhood cancers in the United
6 States, with hepatoblastoma increasing by approxi-
7 mately 2 percent per year to and now approaching
8 1.7 cases per million children; although the overall
9 5-year relative survival rate from a pediatric primary
10 liver tumor is about 77 percent, survival falls below
11 60 percent for adolescents and for tumors diagnosed
12 with distant metastases;

13 (3) biliary atresia, a neonatal malformation of
14 the bile ducts occurring in roughly 1 in 12,000 live
15 births and the leading indication for infant liver
16 transplantation, shows transplant-free survival that
17 roughly doubles when a Kasai portoenterostomy is
18 performed before 60 days of life;

19 (4) clinically validated early-warning tools can
20 detect cholestatic liver disease in time for thera-
21 peutic intervention, including—

22 (A) routine direct-bilirubin measurement in
23 the newborn heel-stick panel, which when used
24 in multi-center, United States pilots detected

1 100 percent of biliary-atresia cases with mini-
2 mal false positives; and

3 (B) improved education of pediatric pri-
4 mary care providers to be alert to early warning
5 signs of biliary atresia with expedited referral
6 to pediatric liver specialists;

7 (5) despite recent liver donor allocation re-
8 forms, more than 1 in 10 infants and more than 1
9 in 20 older children on the United States liver-trans-
10 plant wait list die before receiving a graft;

11 (6) living-donor liver transplantation expands
12 the pediatric organ pool and delivers equivalent or
13 superior 1-year, 3-year, and 5-year graft and patient
14 survival compared with deceased-donor grafts; and

15 (7) many children with rare liver diseases, in-
16 cluding liver cancer, are only able to receive timely
17 transplants through physician advocacy to petition
18 for exceptions to the standard listing practices.

19 **SEC. 3. PEDIATRIC LIVER DISEASE OUTCOMES AND NEW-**
20 **BORN SCREENING PANELS.**

21 (a) GAO STUDY.—The Comptroller General of the
22 United States shall conduct a study on—

23 (1) federally funded initiatives to improve early
24 detection and treatment of pediatric liver tumors, in-
25 cluding education programs for healthcare providers,

1 as well as research to identify risk factors and inno-
2 vative therapeutic strategies;

3 (2) to the extent reliable data are available,
4 what is known about trends in pediatric liver-trans-
5 plant wait-list mortality, including a breakdown by
6 geography, race, insurance status, diagnosis, and se-
7 verity of illness; and

8 (3) to the extent reliable data are available,
9 what is known about the cost effectiveness of adding
10 direct-bilirubin as a screening test for biliary atresia
11 and other cholestatic liver diseases to State new-
12 born-screening panels.

13 (b) REPORT TO CONGRESS.—Not later than one year
14 after the date of enactment of this Act, the Comptroller
15 General shall transmit to Congress a report on the results
16 of the study.

17 **SEC. 4. PUBLIC EDUCATION PROGRAM.**

18 (a) IN GENERAL.—The Secretary of Health and
19 Human Services, acting through the Administrator for the
20 Health Resources and Services Administration, in con-
21 sultation with the Director of the Centers for Disease Con-
22 trol and Prevention (in this section referred to as the
23 “CDC”), shall carry out a public education program under
24 which the Secretary shall develop and disseminate plain-
25 language materials on—

- 1 (1) early signs of pediatric liver disease; and
2 (2) the option and safety of living liver dona-
3 tion.

4 (b) IMPLEMENTATION.—In carrying out the program
5 under subsection (a), the Secretary may—

- 6 (1) coordinate implementation of the program
7 with programs of the CDC, including the National
8 Comprehensive Cancer Control Program (or any suc-
9 cessor campaign); and
10 (2) in addition to the program referred to in
11 paragraph (1), disseminate materials developed
12 under this section through any other public-edu-
13 cation initiative of the Department of Health and
14 Human Services that promotes liver-disease preven-
15 tion, pediatric cancer awareness, or living-organ do-
16 nation.

17 (c) GAO REPORT TO CONGRESS.—Not later than 3
18 years after the date on which the Secretary initiates the
19 program under subsection (a), the Comptroller General of
20 the United States shall transmit to Congress a report on
21 the results of the program.

22 (d) FUNDING.—No additional funds are authorized
23 to be appropriated for the purpose of carrying out this
24 section.

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