

118TH CONGRESS  
1ST SESSION

# H. R. 5012

To improve research and data collection on stillbirths, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

JULY 27, 2023

Mrs. KIM of California (for herself, Ms. CASTOR of Florida, Mr. JOYCE of Ohio, Ms. KELLY of Illinois, Mr. BACON, Ms. LOIS FRANKEL of Florida, Mr. KILMER, Mr. FITZPATRICK, Ms. NORTON, Ms. BLUNT ROCHESTER, Ms. SHERRILL, Mrs. TRAHAN, and Mrs. HINSON) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## A BILL

To improve research and data collection on stillbirths, 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 “Stillbirth Health Im-  
5 provement and Education for Autumn Act of 2023” or  
6 the “SHINE for Autumn Act of 2023”.

1 **SEC. 2. STILLBIRTH RESEARCH AND DATA COLLECTION IM-**  
2 **PROVEMENTS.**

3 Title III of the Public Health Service Act is amended  
4 by inserting after section 317L–1 of such Act (42 U.S.C.  
5 247b–13a) the following:

6 **“SEC. 317L–2. STILLBIRTH RESEARCH AND DATA COLLEC-**  
7 **TION IMPROVEMENTS.**

8 “(a) STILLBIRTH SURVEILLANCE AND RISK FACTOR  
9 STUDIES.—

10 “(1) IN GENERAL.—The Secretary may award  
11 grants to States for purposes of—

12 “(A) conducting surveillance and collecting  
13 data, including from existing datasets like State  
14 or sub-State maternal mortality data and Fetal  
15 and Infant Mortality Review data, with respect  
16 to stillbirths for public health and research pur-  
17 poses;

18 “(B) building State and local public health  
19 capacity to assess stillbirth data; and

20 “(C) collecting and reporting data on still-  
21 birth risk factors, including any quantifiable  
22 outcomes with respect to such risk factors.

23 “(2) CONDITION.—As a condition of receipt of  
24 funds under this section, all data collected shall be  
25 in a manner that protects personal privacy and in a

1 manner that is consistent with applicable Federal  
2 and State privacy law, at a minimum.

3 “(3) AUTHORIZATION OF APPROPRIATIONS.—

4 To carry out this subsection, there is authorized to  
5 be appropriated \$5,000,000 for each of fiscal years  
6 2024 through 2028.

7 “(b) GUIDELINES AND EDUCATIONAL AWARENESS  
8 MATERIALS.—

9 “(1) IN GENERAL.—The Secretary shall—

10 “(A) issue guidelines to State departments  
11 of health and State and local vital statistics  
12 units on—

13 “(i) collecting data on stillbirth from  
14 health care providers, and with the consent  
15 of the woman who experienced the still-  
16 birth, including any such data with respect  
17 to the clinical history, postmortem exam-  
18 ination, and placental pathology; and

19 “(ii) improving processes and training  
20 related to stillbirth data collection and re-  
21 porting to ensure standardization and com-  
22 pleteness of data; and

23 “(B) develop, and make publicly available,  
24 educational awareness materials on stillbirths.

1           “(2) CONSULTATION.—In carrying out para-  
2 graph (1), the Secretary may consult with—

3           “(A) national health care professional as-  
4 sociations;

5           “(B) national associations representing  
6 State and local public health officials;

7           “(C) organizations that assist families with  
8 burial support and bereavement services;

9           “(D) nurses and nurse practitioners;

10          “(E) obstetricians and gynecologists;

11          “(F) pediatricians;

12          “(G) maternal-fetal medicine specialists;

13          “(H) nurse midwives and midwives;

14          “(I) mental health professionals;

15          “(J) statisticians;

16          “(K) individuals who have experienced a  
17 stillbirth; and

18          “(L) advocacy organizations representing  
19 such individuals.

20          “(3) AUTHORIZATION OF APPROPRIATIONS.—

21          To carry out this subsection, there is authorized to  
22 be appropriated \$1,000,000 for each of fiscal years  
23 2024 through 2028.

24          “(c) VITAL STATISTICS UNIT DEFINED.—In this sec-  
25 tion, the term ‘vital statistics unit’ means the entity that

1 is responsible for maintaining vital records for a State,  
2 or a political subdivision of such State, including official  
3 records of live births, deaths, fetal deaths, marriages, di-  
4 vorces, and annulments.”.

5 **SEC. 3. PERINATAL PATHOLOGY FELLOWSHIPS.**

6 The Public Health Service Act is amended by insert-  
7 ing after section 1122 of such Act (42 U.S.C. 300e-12)  
8 the following:

9 **“SEC. 1123. IMPROVING PERINATAL PATHOLOGY.**

10 “(a) IN GENERAL.—The Secretary shall incorporate  
11 into an existing training program a Perinatal Pathology  
12 Fellowship Program, a Postdoctoral Research Fellowship  
13 on Factors Associated with Stillbirth Program, or both.

14 “(b) ACTIVITIES.—Each program incorporated under  
15 subsection (a) shall—

16 “(1) provide training in perinatal autopsy pa-  
17 thology;

18 “(2) provide practice-based learning opportuni-  
19 ties to foster exchange and connection with State ef-  
20 forts concerning fetal death review that are sup-  
21 ported under title V of the Social Security Act;

22 “(3) conduct research on, and improve data col-  
23 lection with respect to, stillbirths, including through  
24 fetal autopsies; and

1           “(4) address challenges in stillbirth education,  
2           research, and data collection.

3           “(c) AUTHORIZATION OF APPROPRIATIONS.—There  
4 is authorized to be appropriated to carry out this section  
5 \$3,000,000 for each of fiscal years 2024 through 2028.”.

6 **SEC. 4. REPORTS.**

7           (a) EDUCATIONAL GUIDELINES REPORT.—

8           (1) IN GENERAL.—Not later than five years  
9           after the date of enactment of this Act, the Sec-  
10          retary of Health and Human Services shall publish  
11          on a public website of the Department of Health and  
12          Human Services a report with educational guidelines  
13          on stillbirth and stillbirth risk factors.

14          (2) CONTENTS.—Such report shall include, to  
15          the extent practicable and appropriate, the guide-  
16          lines issued and educational awareness materials de-  
17          veloped under section 317L–2 of the Public Health  
18          Service Act, as added by section 2 of this Act.

19          (b) PROGRESS REPORT.—Not later than five years  
20          after the date of enactment of this Act, the Secretary of  
21          Health and Human Services shall submit to the Congress  
22          a comprehensive report on the progress and effectiveness  
23          of each program under section 1123 of the Public Health  
24          Service Act, as added by section 3 of this Act.

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