## Union Calendar No. <sup>117TH CONGRESS</sup> <sup>1ST SESSION</sup> H.R.5487

[Report No. 117-]

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

### IN THE HOUSE OF REPRESENTATIVES

October 5, 2021

Ms. HERRERA BEUTLER (for herself, Ms. ROYBAL-ALLARD, Ms. CASTOR of Florida, and Mr. MULLIN) introduced the following bill; which was referred to the Committee on Energy and Commerce

NOVEMBER --, 2021

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in italic]

[For text of introduced bill, see copy of bill as introduced on October 5, 2021]

# 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 2021" or the   |
| 6  | "SHINE for Autumn Act of 2021".  |
| 7  | SEC. 2. STILLBIRTH RESEARCH AND DATA COLLECTION IM-  |
| 8  | PROVEMENTS.  |
| 9  | Title III of the Public Health Service Act is amended  |
| 10   | by inserting after section 317L-1 of such Act (42 U.S.C.   |
| 11   | 247b–13a) the following:   |
| 12   | "SEC. 317L-2. STILLBIRTH RESEARCH AND DATA COLLEC-   |
|  |  |
| 13   | TION IMPROVEMENTS.   |
| 13<br>14                                     | tion improvements.<br>"(a) Stillbirth Surveillance and Risk Factor   |
|  |  |
| 14   | "(a) Stillbirth Surveillance and Risk Factor   |
| 14<br>15                                     | "(a) Stillbirth Surveillance and Risk Factor<br>Studies.—  |
| 14<br>15<br>16                               | "(a) Stillbirth Surveillance and Risk Factor<br>Studies.—<br>"(1) In general.—The Secretary may award  |
| 14<br>15<br>16<br>17                         | "(a) STILLBIRTH SURVEILLANCE AND RISK FACTOR<br>STUDIES.—<br>"(1) IN GENERAL.—The Secretary may award<br>grants to States for purposes of—   |
| 14<br>15<br>16<br>17<br>18                   | "(a) STILLBIRTH SURVEILLANCE AND RISK FACTOR<br>STUDIES.—<br>"(1) IN GENERAL.—The Secretary may award<br>grants to States for purposes of—<br>"(A) conducting surveillance and collecting  |
| 14<br>15<br>16<br>17<br>18<br>19             | "(a) STILLBIRTH SURVEILLANCE AND RISK FACTOR<br>STUDIES.—<br>"(1) IN GENERAL.—The Secretary may award<br>grants to States for purposes of—<br>"(A) conducting surveillance and collecting<br>data with respect to stillbirths;   |
| 14<br>15<br>16<br>17<br>18<br>19<br>20       | "(a) STILLBIRTH SURVEILLANCE AND RISK FACTOR<br>STUDIES.—<br>"(1) IN GENERAL.—The Secretary may award<br>grants to States for purposes of—<br>"(A) conducting surveillance and collecting<br>data with respect to stillbirths;<br>"(B) building State and local public health  |
| 14<br>15<br>16<br>17<br>18<br>19<br>20<br>21 | "(a) STILLBIRTH SURVEILLANCE AND RISK FACTOR<br>STUDIES.—<br>"(1) IN GENERAL.—The Secretary may award<br>grants to States for purposes of—<br>"(A) conducting surveillance and collecting<br>data with respect to stillbirths;<br>"(B) building State and local public health<br>capacity to assess stillbirth data; and |

| 1  | "(2) Authorization of Appropriations.—To                 |
|----|--|
| 2  | carry out this subsection, there is authorized to be ap- |
| 3  | propriated \$5,000,000 for each of fiscal years 2022     |
| 4  | through 2026.  |
| 5  | "(b) Guidelines and Educational Awareness Ma-            |
| 6  | TERIALS.—  |
| 7  | "(1) IN GENERAL.—The Secretary shall—                    |
| 8  | "(A) issue guidelines to State departments               |
| 9  | of health and State and local vital statistics           |
| 10 | units on—  |
| 11 | "(i) collecting data on stillbirth from                  |
| 12 | health care providers, and with the consent              |
| 13 | of the family involved, including any such               |
| 14 | data with respect to the clinical history,               |
| 15 | postmortem examination, and placental pa-                |
| 16 | thology;   |
| 17 | "(ii) sharing such data with Federal                     |
| 18 | agencies determined appropriate by the Di-               |
| 19 | rector of the Centers for Disease Control and            |
| 20 | Prevention; and  |
| 21 | "(iii) improving processes and train-                    |
| 22 | ing related to stillbirth data collection and            |
| 23 | reporting to ensure standardization and                  |
| 24 | completeness of data; and                                |
|    |  |

| 1  | "(B) develop, and make publicly available,               |
|----|--|
| 2  | educational awareness materials on stillbirths.          |
| 3  | "(2) Consultation.—In carrying out para-                 |
| 4  | graph (1), the Secretary may consult with—               |
| 5  | "(A) national health care professional asso-             |
| 6  | ciations;  |
| 7  | ``(B) national associations representing                 |
| 8  | State and local public health officials;                 |
| 9  | (C) organizations that assist families with              |
| 10 | burial support and bereavement services;                 |
| 11 | "(D) nurses and nurse practitioners;                     |
| 12 | ``(E) obstetricians and gynecologists;                   |
| 13 | (F) pediatricians;                                       |
| 14 | "(G) maternal-fetal medicine specialists;                |
| 15 | "(H) midwives;   |
| 16 | "(I) mental health professionals;                        |
| 17 | $``(J) \ statisticians;$                                 |
| 18 | ``(K) individuals who have experienced a                 |
| 19 | stillbirth; and  |
| 20 | ``(L) advocacy organizations representing                |
| 21 | such individuals.  |
| 22 | "(3) Authorization of Appropriations.—To                 |
| 23 | carry out this subsection, there is authorized to be ap- |
| 24 | propriated \$1,000,000 for each of fiscal years 2022     |
| 25 | through 2026.  |

1 "(c) VITAL STATISTICS UNIT DEFINED.—In this sec-2 tion, the term 'vital statistics unit' means the entity that 3 is responsible for maintaining vital records for a State, or 4 a political subdivision of such State, including official 5 records of live births, deaths, fetal deaths, marriages, di-6 vorces, and annulments.".

#### 7 SEC. 3. PERINATAL PATHOLOGY FELLOWSHIPS.

8 The Public Health Service Act is amended by inserting
9 after section 1122 of such Act (42 U.S.C. 300c-12) the fol10 lowing:

### 11 "SEC. 1123. IMPROVING PERINATAL PATHOLOGY.

12 "(a) IN GENERAL.—The Secretary shall establish and 13 implement, or incorporate into an existing training pro-14 gram, a Perinatal Pathology Fellowship Program or a 15 Postdoctoral Research Fellowship on Factors Associated 16 with Stillbirth Program to—

17 "(1) provide training in perinatal autopsy pa18 thology;

- 19 "(2) conduct research on, and improve data col20 lection through fetal autopsies with respect to, still-
- 21 *birth; and*

22 "(3) address challenges in stillbirth education,
23 research, and data collection.

"(b) AUTHORIZATION OF APPROPRIATIONS.—There
 are authorized to be appropriated to carry out this section
 \$3,000,000 for each of fiscal years 2022 through 2026.".

4 SEC. 4. REPORTS.

5 (a) Educational Guidelines Report.—

6 (1) IN GENERAL.—Not later than five years after 7 the date of enactment of this Act, the Secretary of 8 Health and Human Services shall publish on a public 9 website of the Department of Health and Human 10 Services a report with educational guidelines on still-11 birth and stillbirth risk factors.

(2) CONTENTS.—Such report shall include, to the
extent practicable and appropriate, the guidelines
issued and educational awareness materials developed
under section 317L-2 of the Public Health Service
Act, as added by section 2 of this Act.

17 (b) PROGRESS REPORT.—Not later than five years 18 after the date of enactment of this Act, the Secretary of 19 Health and Human Services shall submit to the Congress 20 a comprehensive report on the progress and effectiveness of 21 the Perinatal Pathology Fellowship Program established 22 under section 1123 of the Public Health Service Act, as 23 added by section 3 of this Act.