

# 118TH CONGRESS 1ST SESSION H.R. 5012

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

### 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

## 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. 300c–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—
- "(1) provide training in perinatal autopsy pa-
- thology;
- 18 "(2) provide practice-based learning opportuni-
- ties to foster exchange and connection with State ef-
- 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-
- lection with respect to, stillbirths, including through
- 24 fetal autopsies; and

- 6 1 "(4) address challenges in stillbirth education, 2 research, and data collection. 3 "(c) Authorization of Appropriations.—There is authorized to be appropriated to carry out this section \$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.