

STILLBIRTH HEALTH IMPROVEMENT AND EDUCATION
FOR AUTUMN ACT OF 2021

DECEMBER 8, 2021.—Committed to the Committee of the Whole House on the State
of the Union and ordered to be printed

Mr. PALLONE, from the Committee on Energy and Commerce,
submitted the following

R E P O R T

[To accompany H.R. 5487]

The Committee on Energy and Commerce, to whom was referred
the bill (H.R. 5487) to improve research and data collection on still-
births, and for other purposes, having considered the same, reports
favorably thereon with an amendment and recommends that the
bill as amended do pass.

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The amendment is as follows:

Strike all after the enacting clause and insert the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the “Stillbirth Health Improvement and Education for
Autumn Act of 2021” or the “SHINE for Autumn Act of 2021”.

SEC. 2. STILLBIRTH RESEARCH AND DATA COLLECTION IMPROVEMENTS.

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

“SEC. 317L–2. STILLBIRTH RESEARCH AND DATA COLLECTION IMPROVEMENTS.

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

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

“(A) conducting surveillance and collecting data with respect to stillbirths;

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

“(C) collecting and reporting data on stillbirth risk factors, including any quantifiable outcomes with respect to such risk factors.

“(2) AUTHORIZATION OF APPROPRIATIONS.—To carry out this subsection, there is authorized to be appropriated \$5,000,000 for each of fiscal years 2022 through 2026.

“(b) GUIDELINES AND EDUCATIONAL AWARENESS MATERIALS.—

“(1) IN GENERAL.—The Secretary shall—

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

“(i) collecting data on stillbirth from health care providers, and with the consent of the family involved, including any such data with respect to the clinical history, postmortem examination, and placental pathology;

“(ii) sharing such data with Federal agencies determined appropriate by the Director of the Centers for Disease Control and Prevention; and

“(iii) improving processes and training related to stillbirth data collection and reporting to ensure standardization and completeness of data; and

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

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

“(A) national health care professional associations;

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

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

“(D) nurses and nurse practitioners;

“(E) obstetricians and gynecologists;

“(F) pediatricians;

“(G) maternal-fetal medicine specialists;

“(H) midwives;

“(I) mental health professionals;

“(J) statisticians;

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

“(L) advocacy organizations representing such individuals.

“(3) AUTHORIZATION OF APPROPRIATIONS.—To carry out this subsection, there is authorized to be appropriated \$1,000,000 for each of fiscal years 2022 through 2026.

“(c) VITAL STATISTICS UNIT DEFINED.—In this section, the term ‘vital statistics unit’ means the entity that is responsible for maintaining vital records for a State, or a political subdivision of such State, including official records of live births, deaths, fetal deaths, marriages, divorces, and annulments.”.

SEC. 3. PERINATAL PATHOLOGY FELLOWSHIPS.

The Public Health Service Act is amended by inserting after section 1122 of such Act (42 U.S.C. 300c–12) the following:

“SEC. 1123. IMPROVING PERINATAL PATHOLOGY.

“(a) IN GENERAL.—The Secretary shall establish and implement, or incorporate into an existing training program, a Perinatal Pathology Fellowship Program or a Postdoctoral Research Fellowship on Factors Associated with Stillbirth Program to—

“(1) provide training in perinatal autopsy pathology;

“(2) conduct research on, and improve data collection through fetal autopsies with respect to, stillbirth; and

“(3) address challenges in stillbirth education, 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.”.

SEC. 4. REPORTS.

(a) EDUCATIONAL GUIDELINES REPORT.—

(1) IN GENERAL.—Not later than five years after the date of enactment of this Act, the Secretary of Health and Human Services shall publish on a public website of the Department of Health and Human Services a report with educational guidelines on stillbirth 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.

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

I. PURPOSE AND SUMMARY

H.R. 5487, the “Stillbirth Health Improvement and Education for Autumn Act of 2021,” or the “SHINE for Autumn Act of 2021,” seeks to improve research and data collection on stillbirths by authorizing grants to states for surveillance and data collection relating to stillbirth and stillbirth risk factors, developing guidelines and educational materials for State departments of health, and establishing a Perinatal Pathology Fellowship Program at the National Institutes of Health (NIH) to increase research on stillbirth. The legislation authorizes \$9 million for these activities for each of fiscal years 2022 through 2026.

II. BACKGROUND AND NEED FOR LEGISLATION

Stillbirth affects one in 160 births—approximately 24,000 babies are stillborn in the United States each year.¹ That is 10 times as many deaths as those cause by Sudden Infant Death Syndrome (SIDS).^{2 3} Medical advances, including improved prenatal care, have reduced the number of late and term stillbirths, but the rate of early stillbirth has remained relatively unchanged. Health disparities also play a key role in stillbirth, as research conducted by the Centers for Disease Control and Prevention (CDC) found that Black mothers were more than twice as likely to experience stillbirth compared to Hispanic and white mothers.⁴

Despite these reductions in stillbirths, the causes of stillbirth have not been explored extensively through research. There are a number of factors for the lack of thorough research in the United States and globally, including notably a lack of uniformly collected data, a lack of consensus on interventions, health disparities present in low-income communities or countries, and a lack of will-

¹Centers for Disease Control and Prevention, *Stillbirth* (www.cdc.gov/ncbddd/stillbirth/facts.html) (Nov. 16, 2020).

²Centers for Disease Control and Prevention, *Articles and Key Findings about Stillbirth* (<https://www.cdc.gov/ncbddd/stillbirth/articles.html>) (Sept. 17, 2020).

³Centers for Disease Control and Prevention, *Sudden Unexpected Infant Death and Sudden Infant Death Syndrome* (<https://www.cdc.gov/SIDS/>) (Dec. 31, 2020).

⁴See Note 2.

ing participants in further research.⁵ There are also social factors and stigma that reduce the visibility of stillbirths, including the desire for privacy by a family in mourning.⁶

H.R. 5487 is named in honor of Autumn Joy, who was stillborn on July 8, 2011. The legislation seeks to bolster research on stillbirths and stillbirth risk factors to help lower the United States' stillbirth rate. H.R. 5487 would provide resources to State and local health departments to help improve data collection around stillbirths and increase education and awareness around the issue of stillbirth in the United States. The data collected pursuant to the legislation is only intended for the purposes of informing public health research and improving health outcomes related to stillbirths.

III. COMMITTEE HEARINGS

For the purposes of section 3(c) of rule XIII of the Rules of the House of Representatives, the following hearing was used to develop or consider H.R. 5487:

The Subcommittee on Health held a legislative hearing on October 20, 2021, entitled “Enhancing Public Health: Legislation to Protect Children and Families.” The Subcommittee received testimony from the following witnesses:

- Bruce L. Cassis, D.D.S., M.A.G.D., President, Academy of General Dentistry;
- Raymond DuBois, M.D., Ph.D., Former President, American Association for Cancer Research;
- Donald M. Lloyd-Jones, M.D., Sc.M., President, American Heart Association;
- Ellyn Miller, President and Founder, Smashing Walnuts Foundation;
- Rick Nolan, Former U.S. Representative (MN);
- Jenny Radesky, M.D., Assistant Professor of Pediatrics, University of Michigan Medical School; and
- Stacey Stewart, President and CEO, March of Dimes.

IV. COMMITTEE CONSIDERATION

Representatives Jaime Herrera Beutler (R-WA), Lucille Roybal-Allard (D-CA), Kathy Castor (D-FL), and Markwayne Mullin (R-OK) introduced H.R. 5487, the “SHINE for Autumn Act of 2021,” on October 5, 2021, and it was referred to the Committee on Energy and Commerce. Subsequently, on October 6, 2021, H.R. 5487 was referred to the Subcommittee on Health. A legislative hearing was held on the bill on October 20, 2021.

On November 4, 2021, the Subcommittee on Health met in open markup session, pursuant to notice, to consider H.R. 5487 and 8 other bills. During consideration of the bill, an amendment offered by Representative Mullin was agreed to by a voice vote. Upon conclusion of consideration of the bill, the Subcommittee on Health agreed to report the bill favorably to the full Committee, amended, by a voice vote.

⁵Joy E. Lawn, et al., *3.2 million stillbirths: epidemiology and overview of the evidence review*, BMC pregnancy and childbirth vol. 9 (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2679408/) (2009).

⁶*Id.*

On November 17, 2021, the full Committee met in open markup session, pursuant to notice, to consider H.R. 5487 and 11 other bills. During consideration of the bill, an amendment offered by Representative Mullin was agreed to by a voice vote. Upon conclusion of consideration of the bill, the full Committee agreed to a motion on final passage offered by Representative Pallone (D–NJ), Chairman of the Committee, to order H.R. 5487 reported favorably to the House, as amended, by a voice vote.

V. COMMITTEE VOTES

Clause 3(b) of rule XIII of the Rules of the House of Representatives requires the Committee to list each record vote on the motion to report legislation and amendments thereto. The Committee advises that there were no record votes taken on H.R. 5487.

VI. OVERSIGHT FINDINGS

Pursuant to clause 3(c)(1) of rule XIII and clause 2(b)(1) of rule X of the Rules of the House of Representatives, the oversight findings and recommendations of the Committee are reflected in the descriptive portion of the report.

VII. NEW BUDGET AUTHORITY, ENTITLEMENT AUTHORITY, AND TAX EXPENDITURES

Pursuant to 3(c)(2) of rule XIII of the Rules of the House of Representatives, the Committee adopts as its own the estimate of new budget authority, entitlement authority, or tax expenditures or revenues contained in the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

The Committee has requested but not received from the Director of the Congressional Budget Office a statement as to whether this bill contains any new budget authority, spending authority, credit authority, or an increase or decrease in revenues or tax expenditures.

VIII. FEDERAL MANDATES STATEMENT

The Committee adopts as its own the estimate of Federal mandates prepared by the Director of the Congressional Budget Office pursuant to section 423 of the Unfunded Mandates Reform Act.

IX. STATEMENT OF GENERAL PERFORMANCE GOALS AND OBJECTIVES

Pursuant to clause 3(c)(4) of rule XIII, the general performance goal or objective of this legislation is to improve research and data collection on stillbirths.

X. DUPLICATION OF FEDERAL PROGRAMS

Pursuant to clause 3(c)(5) of rule XIII, no provision of H.R. 5487 is known to be duplicative of another Federal program, including any program that was included in a report to Congress pursuant to section 21 of Public Law 111–139 or the most recent Catalog of Federal Domestic Assistance.

XI. COMMITTEE COST ESTIMATE

Pursuant to clause 3(d)(1) of rule XIII, the Committee adopts as its own the cost estimate prepared by the Director of the Congressional Budget Office pursuant to section 402 of the Congressional Budget Act of 1974.

XII. EARMARKS, LIMITED TAX BENEFITS, AND LIMITED TARIFF BENEFITS

Pursuant to clause 9(e), 9(f), and 9(g) of rule XXI, the Committee finds that H.R. 5487 contains no earmarks, limited tax benefits, or limited tariff benefits.

XIII. ADVISORY COMMITTEE STATEMENT

No advisory committee within the meaning of section 5(b) of the Federal Advisory Committee Act was created by this legislation.

XIV. APPLICABILITY TO LEGISLATIVE BRANCH

The Committee finds that the legislation does not relate to the terms and conditions of employment or access to public services or accommodations within the meaning of section 102(b)(3) of the Congressional Accountability Act.

XV. SECTION-BY-SECTION ANALYSIS OF THE LEGISLATION

Section 1. Short title

Section 1 designates that the short title may be cited as the “Stillbirth Health Improvement and Education for Autumn Act of 2021,” or the “SHINE for Autumn Act of 2021.”

Sec. 2. Stillbirth research and data collection improvements

Section 2 amends the Public Health Service Act, authorizing \$5 million for each of fiscal years 2022 through 2026 for the Secretary of Health and Human Services (HHS) to award grants to States for the purposes of (1) conducting surveillance and collecting data with respect to stillbirths, (2) building State and local public health capacity to assess stillbirth data, and (3) collecting and reporting on stillbirth risk factors, including any quantifiable outcomes with respect to such risk factors.

Section 2 also directs the Secretary of HHS to issue guidelines to State departments of health and State and local vital statistics units on (1) collecting data on stillbirth from health care providers, and with the consent of the family involved, (2) sharing such relevant data with Federal agencies determined appropriate by the CDC Director, and (3) improving processes and training related to stillbirth data collection and reporting to ensure standardization and completeness of data. The Secretary of HHS is also required to develop and make publicly available educational awareness materials on stillbirths. In carrying out these activities, the Secretary of HHS may consult with national health care professional associations, national associations representing State and local public health officials, organizations that assist families with burial support and bereavement services, nurses and nurse practitioners, obstetricians and gynecologists, pediatricians, maternal-fetal medi-

cine specialists, midwives, mental health professionals, statisticians, individuals who have experienced a stillbirth, and advocacy organizations representing such individuals. This section authorizes \$1 million for each of fiscal years 2022 through 2026 for those purposes.

This section defines the term “vital statistics unit” as the entity that is responsible for maintaining vital records for a State, or a political subdivision of such State, including official records of live births, deaths, fetal deaths, marriages, divorces, and annulments.

Sec. 3. Perinatal Pathology Fellowships

Section 3 authorizes \$3 million for each of fiscal years 2022 through 2026 for the Secretary of HHS to establish and implement, or incorporate into an existing training program, a Perinatal Pathology Fellowship Program, or a Postdoctoral Research Fellowship on Factors Associated with Stillbirth Program. These programs should aim to (1) provide training in perinatal autopsy pathology, (2) conduct research on and improve data collection through fetal autopsies with respect to stillbirth, and (3) address challenges in stillbirth education, research, and data collection.

Sec. 4. Reports

Section 4 directs the Secretary of HHS to, no later than five years after enactment, publish on HHS’s public website a report with educational guidelines on stillbirth and stillbirth risk factors. The report shall include, to the extent practicable and appropriate, the guidelines issued and educational awareness materials developed under Section 2 of this legislation. This section also directs the Secretary of HHS to submit to Congress a comprehensive report on the progress and effectiveness of the Perinatal Pathology Fellowship Program established under Section 3 of this legislation.

XVI. CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3(e) of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (new matter is printed in italics and existing law in which no change is proposed is shown in roman):

PUBLIC HEALTH SERVICE ACT

* * * * *

TITLE III—GENERAL POWERS AND DUTIES OF PUBLIC HEALTH SERVICE

* * * * *

PART B—FEDERAL-STATE COOPERATION

* * * * *

SEC. 317L-2. STILLBIRTH RESEARCH AND DATA COLLECTION IMPROVEMENTS.

(a) *STILLBIRTH SURVEILLANCE AND RISK FACTOR STUDIES.*—

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

(A) conducting surveillance and collecting data with respect to stillbirths;

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

(C) collecting and reporting data on stillbirth risk factors, including any quantifiable outcomes with respect to such risk factors.

(2) *AUTHORIZATION OF APPROPRIATIONS.*—To carry out this subsection, there is authorized to be appropriated \$5,000,000 for each of fiscal years 2022 through 2026.

(b) *GUIDELINES AND EDUCATIONAL AWARENESS MATERIALS.*—

(1) *IN GENERAL.*—The Secretary shall—

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

(i) collecting data on stillbirth from health care providers, and with the consent of the family involved, including any such data with respect to the clinical history, postmortem examination, and placental pathology;

(ii) sharing such data with Federal agencies determined appropriate by the Director of the Centers for Disease Control and Prevention; and

(iii) improving processes and training related to stillbirth data collection and reporting to ensure standardization and completeness of data; and

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

(2) *CONSULTATION.*—In carrying out paragraph (1), the Secretary may consult with—

(A) national health care professional associations;

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

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

(D) nurses and nurse practitioners;

(E) obstetricians and gynecologists;

(F) pediatricians;

(G) maternal-fetal medicine specialists;

(H) midwives;

(I) mental health professionals;

(J) statisticians;

(K) individuals who have experienced a stillbirth; and

(L) advocacy organizations representing such individuals.

(3) *AUTHORIZATION OF APPROPRIATIONS.*—To carry out this subsection, there is authorized to be appropriated \$1,000,000 for each of fiscal years 2022 through 2026.

(c) *VITAL STATISTICS UNIT DEFINED.*—In this section, the term “vital statistics unit” means the entity that is responsible for maintaining vital records for a State, or a political subdivision of such State, including official records of live births, deaths, fetal deaths, marriages, divorces, and annulments.

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TITLE XI—GENETIC DISEASES, HEMOPHILIA PROGRAMS,
AND SUDDEN INFANT DEATH SYNDROME

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PART B—SUDDEN UNEXPECTED INFANT DEATH, SUDDEN INFANT
DEATH SYNDROME, AND SUDDEN UNEXPECTED DEATH IN CHILD-
HOOD

* * * * *

SEC. 1123. IMPROVING PERINATAL PATHOLOGY.

(a) *IN GENERAL.*—The Secretary shall establish and implement, or incorporate into an existing training program, a *Perinatal Pathology Fellowship Program* or a *Postdoctoral Research Fellowship on Factors Associated with Stillbirth Program* to—

- (1) *provide training in perinatal autopsy pathology;*
- (2) *conduct research on, and improve data collection through fetal autopsies with respect to, stillbirth; and*
- (3) *address challenges in stillbirth education, 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.

* * * * *