

***In the House of Representatives, U. S.,***

*December 10, 2020.*

*Resolved*, That the bill from the Senate (S. 1130) entitled “An Act to amend the Public Health Service Act to improve the health of children and help better understand and enhance awareness about unexpected sudden death in early life.”, do pass with the following

**AMENDMENT:**

Strike all after section 1 and insert the following:

1 ***SEC. 2. AMENDMENT TO THE PUBLIC HEALTH SERVICE ACT.***

2 *Part B of title XI of the Public Health Service Act*

3 *(42 U.S.C. 241 et seq.) is amended—*

4 *(1) in the part heading, by striking “SUDDEN*

5 ***INFANT DEATH SYNDROME”*** and inserting “***SUD-***

6 ***DEN UNEXPECTED INFANT DEATH, SUDDEN IN-***

7 ***FANT DEATH SYNDROME, AND SUDDEN UNEX-***

8 ***PECTED DEATH IN CHILDHOOD”***; and

9 *(2) by inserting before section 1122 the following:*

10 ***“SEC. 1121. ADDRESSING SUDDEN UNEXPECTED INFANT***

11 ***DEATH AND SUDDEN UNEXPECTED DEATH IN***

12 ***CHILDHOOD.***

13 *“(a) IN GENERAL.—The Secretary may develop, sup-*

14 *port, or maintain programs or activities to address sudden*

1 *unexpected infant death and sudden unexpected death in*  
2 *childhood, including by—*

3           “(1) *continuing to support the Sudden Unex-*  
4 *pected Infant Death and Sudden Death in the Young*  
5 *Case Registry of the Centers for Disease Control and*  
6 *Prevention and other fatality case reporting systems*  
7 *that include data pertaining to sudden unexpected in-*  
8 *fant death and sudden unexpected death in childhood,*  
9 *as appropriate, including such systems supported by*  
10 *the Health Resources and Services Administration, in*  
11 *order to—*

12           “(A) *increase the number of States and ju-*  
13 *risdictions participating in such registries or*  
14 *systems; and*

15           “(B) *improve the utility of such registries*  
16 *or systems, which may include—*

17           “(i) *making summary data available*  
18 *to the public in a timely manner on the*  
19 *internet website of the Department of*  
20 *Health and Human Services, in a manner*  
21 *that, at a minimum, protects personal pri-*  
22 *vacancy to the extent required by applicable*  
23 *Federal and State law; and*

24           “(ii) *making the data submitted to*  
25 *such registries or systems available to re-*

1           *searchers, in a manner that, at a min-*  
2           *imum, protects personal privacy to the ex-*  
3           *tent required by applicable Federal and*  
4           *State law; and*

5           “(2) *awarding grants or cooperative agreements*  
6           *to States, Indian Tribes, and Tribal organizations for*  
7           *purposes of—*

8                   “(A) *supporting fetal and infant mortality*  
9                   *and child death review programs for sudden un-*  
10                   *expected infant death and sudden unexpected*  
11                   *death in childhood, including by establishing*  
12                   *such programs at the local level;*

13                   “(B) *improving data collection related to*  
14                   *sudden unexpected infant death and sudden un-*  
15                   *expected death in childhood, including by—*

16                           “(i) *improving the completion of death*  
17                           *scene investigations and comprehensive au-*  
18                           *topsies that include a review of clinical his-*  
19                           *tory and circumstances of death with ap-*  
20                           *propriate ancillary testing; and*

21                           “(ii) *training medical examiners, coro-*  
22                           *ners, death scene investigators, law enforce-*  
23                           *ment personnel, emergency medical techni-*  
24                           *cians, paramedics, emergency department*  
25                           *personnel, and others who perform death*

1           *scene investigations with respect to the*  
2           *deaths of infants and children, as appro-*  
3           *priate;*

4           “(C) *identifying, developing, and imple-*  
5           *menting best practices to reduce or prevent sud-*  
6           *den unexpected infant death and sudden unex-*  
7           *pected death in childhood, including practices to*  
8           *reduce sleep-related infant deaths;*

9           “(D) *increasing the voluntary inclusion, in*  
10          *registries established for the purpose of con-*  
11          *ducting research on sudden unexpected infant*  
12          *death and sudden unexpected death in childhood,*  
13          *of samples of tissues or genetic materials from*  
14          *autopsies that have been collected pursuant to*  
15          *Federal or State law and for which the parent*  
16          *or guardian has provided informed consent for*  
17          *inclusion in such registries;*

18          “(E) *disseminating information and mate-*  
19          *rials to health care professionals and the public*  
20          *on risk factors that contribute to sudden unex-*  
21          *pected infant death and sudden unexpected death*  
22          *in childhood, which may include information on*  
23          *risk factors that contribute to sleep-related sud-*  
24          *den unexpected infant death or sudden unex-*  
25          *pected death in childhood; or*

1           “(F) providing information, referrals, or  
2           peer or follow-up support services to families  
3           who have experienced sudden unexpected infant  
4           death or sudden unexpected death in childhood.

5           “(b) APPLICATION.—To be eligible to receive a grant  
6 or cooperative agreement under subsection (a)(2), a State,  
7 Indian Tribe, or Tribal organization shall submit to the  
8 Secretary an application at such time, in such manner, and  
9 containing such information as the Secretary may require,  
10 including information on how such State will ensure activi-  
11 ties conducted under this section are coordinated with other  
12 federally-funded programs to reduce infant and child mor-  
13 tality, as appropriate.

14           “(c) TECHNICAL ASSISTANCE.—The Secretary shall  
15 provide technical assistance to States, Tribes, and Tribal  
16 organizations receiving a grant or cooperative agreement  
17 under subsection (a)(2) for purposes of carrying out the pro-  
18 gram in accordance with this section.

19           “(d) REPORTING FORMS.—

20           “(1) IN GENERAL.—The Secretary shall, as ap-  
21 propriate, encourage the use of sudden unexpected in-  
22 fant death and sudden unexpected death in childhood  
23 reporting forms developed in collaboration with the  
24 Centers for Disease Control and Prevention to im-  
25 prove the quality of data submitted to the Sudden

1 *Unexpected Infant Death and Sudden Death in the*  
2 *Young Case Registry, and other fatality case report-*  
3 *ing systems that include data pertaining to sudden*  
4 *unexpected infant death and sudden unexpected death*  
5 *in childhood.*

6 “(2) *UPDATE OF FORMS.*—*The Secretary shall*  
7 *assess whether updates are needed to the sudden unex-*  
8 *pected infant death investigation reporting form used*  
9 *by the Centers for Disease Control and Prevention in*  
10 *order to improve the use of such form with other fa-*  
11 *tality case reporting systems supported by the De-*  
12 *partment of Health and Human Services, and shall*  
13 *make such updates as appropriate.*

14 “(e) *DEFINITIONS.*—*In this section:*

15 “(1) *SUDDEN INFANT DEATH SYNDROME.*—*The*  
16 *term ‘sudden infant death syndrome’ means a sudden*  
17 *unexpected infant death that remains unexplained*  
18 *after a thorough case investigation.*

19 “(2) *SUDDEN UNEXPECTED INFANT DEATH.*—  
20 *The term ‘sudden unexpected infant death’ means the*  
21 *sudden death of an infant under 1 year of age that*  
22 *when first discovered did not have an obvious cause.*  
23 *Such term includes such deaths that are explained, as*  
24 *well as deaths that remain unexplained (which are*  
25 *known as sudden infant death syndrome).*

1           “(3) *SUDDEN UNEXPECTED DEATH IN CHILD-*  
2           *HOOD.—The term ‘sudden unexpected death in child-*  
3           *hood’ means the sudden death of a child who is at*  
4           *least 1 year of age but not more than 17 years of age*  
5           *that, when first discovered, did not have an obvious*  
6           *cause. Such term includes such deaths that are ex-*  
7           *plained, as well as deaths that remain unexplained*  
8           *(which are known as sudden unexplained death in*  
9           *childhood).*”

10           “(4) *SUDDEN UNEXPLAINED DEATH IN CHILD-*  
11           *HOOD.—The term ‘sudden unexplained death in*  
12           *childhood’ means a sudden unexpected death in child-*  
13           *hood that remains unexplained after a thorough case*  
14           *investigation.*”

15           “(f) *AUTHORIZATION OF APPROPRIATIONS.—For the*  
16           *purpose of carrying out this section, there is authorized to*  
17           *be appropriated \$12,000,000 for each of fiscal years 2022*  
18           *through 2026.*”

19           **SEC. 3. REPORT TO CONGRESS.**

20           “(a) *IN GENERAL.—Not later than 2 years after the*  
21           *date of enactment of this Act and biennially thereafter, the*  
22           *Secretary of Health and Human Services shall submit to*  
23           *the Committee on Health, Education, Labor, and Pensions*  
24           *of the Senate and the Committee on Energy and Commerce*

1 *of the House of Representatives a report that contains, with*  
2 *respect to the reporting period—*

3 *(1) information regarding the incidence and*  
4 *number of sudden unexpected infant death and sud-*  
5 *den unexpected death in childhood (including the*  
6 *number of such infant and child deaths that remain*  
7 *unexplained after investigation), including, to the ex-*  
8 *tent practicable—*

9 *(A) a summary of such information by ra-*  
10 *cial and ethnic group, and by State;*

11 *(B) aggregate information obtained from*  
12 *death scene investigations and autopsies; and*

13 *(C) recommendations for reducing the inci-*  
14 *dence of sudden unexpected infant death and*  
15 *sudden unexpected death in childhood;*

16 *(2) an assessment of the extent to which various*  
17 *approaches of reducing and preventing sudden unex-*  
18 *pected infant death and sudden unexpected death in*  
19 *childhood have been effective; and*

20 *(3) a description of the activities carried out*  
21 *under section 1121 of the Public Health Service Act*  
22 *(as added by section 2).*

23 *(b) DEFINITIONS.—In this section, the terms “sudden*  
24 *unexpected infant death” and “sudden unexpected death in*  
25 *childhood” have the meanings given such terms in section*

1 *1121 of the Public Health Service Act (as added by section*  
2 *2).*

Attest:

*Clerk.*

116<sup>TH</sup> CONGRESS  
2<sup>D</sup> SESSION

**S. 1130**

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**AMENDMENT**