

Calendar No. 386

115TH CONGRESS
2D SESSION

S. 382

To require the Secretary of Health and Human Services to develop a voluntary registry to collect data on cancer incidence among firefighters.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 15, 2017

Mr. MENENDEZ (for himself, Ms. MURKOWSKI, Mr. RUBIO, Ms. KLOBUCHAR, Mr. MARKEY, Mr. BLUMENTHAL, Mr. DAINES, Mr. BOOKER, Mr. FRANKEN, Mr. SCHUMER, Mr. MCCAIN, Mrs. GILLIBRAND, Mr. TESTER, Mr. NELSON, Mr. SANDERS, Ms. BALDWIN, Ms. COLLINS, Mr. BROWN, Ms. STABENOW, Mr. COONS, Mr. DONNELLY, Mrs. McCASKILL, Mr. MURPHY, Ms. HASSAN, Mr. MERKLEY, Mr. WHITEHOUSE, Mr. VAN HOLLEN, Ms. CORTEZ MASTO, Ms. CANTWELL, Mr. CARDIN, Mr. PETERS, Mrs. FISCHER, Mr. KAINE, Mr. REED, Mr. DURBIN, Ms. WARREN, Mr. CARPER, Mr. SCHATZ, Mr. HEINRICH, Ms. DUCKWORTH, Mrs. FEINSTEIN, Mrs. SHAHEEN, Mr. BLUNT, Mr. KING, Ms. HIRONO, Ms. SMITH, Mr. CASEY, Mr. YOUNG, and Mr. LEAHY) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

APRIL 25, 2018

Reported by Mr. ALEXANDER, with an amendment

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

A BILL

To require the Secretary of Health and Human Services to develop a voluntary registry to collect data on cancer incidence among firefighters.

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 “Firefighter Cancer
 5 Registry Act of 2017”.

6 **SEC. 2. PATIENT REGISTRY FOR FIREFIGHTER CANCER IN-**
 7 **CIDENCE.**

8 (a) IN GENERAL.—The Secretary of Health and
 9 Human Services, acting through the Director of the Cen-
 10 ters for Disease Control and Prevention, shall develop and
 11 maintain, directly or through a grant or cooperative agree-
 12 ment, a voluntary registry of firefighters (referred to in
 13 this section as the “Firefighter Registry”) to collect rel-
 14 evant history and occupational information of such fire-
 15 fighters that can be linked to available cancer registry
 16 data collected by existing State cancer registries.

17 (b) USE OF FIREFIGHTER REGISTRY.—The Fire-
 18 fighter Registry shall be used for the following purposes:

19 (1) To establish and improve collection infra-
 20 structure and activities related to the nationwide
 21 monitoring of the incidence of cancer among fire-
 22 fighters.

23 (2) To collect, consolidate, store, and make
 24 publicly available epidemiological information related
 25 to cancer incidence and trends among firefighters.

1 ~~(c) RELEVANT DATA.—~~

2 ~~(1) IN GENERAL.—~~In carrying out the vol-
 3 untary data collection for purposes of inclusion
 4 under the Firefighter Registry, the Secretary should
 5 seek to include the following information:

6 ~~(A)~~ Identifiable information from a rep-
 7 resentative sample size, as determined by the
 8 Secretary under subsection ~~(d)(2)(A)~~, of volun-
 9 teer, paid-on-call, and career firefighters, inde-
 10 pendent of cancer status or diagnosis.

11 ~~(B)~~ With respect to individual risk factors
 12 and work history of firefighters, available infor-
 13 mation on—

14 ~~(i)~~ basic demographic information, in-
 15 cluding the age of the firefighter involved;

16 ~~(ii)~~ a listing of status of the fire-
 17 fighter as either volunteer, paid-on-call, or
 18 career firefighter;

19 ~~(iii)~~ the number of years on the job
 20 and a detailing of additional employment
 21 experience that was either performed con-
 22 currently alongside firefighting service, be-
 23 fore, or anytime thereafter;

24 ~~(iv)(I)~~ a measure of the number of
 25 fire incidents attended as well as the type

of fire incidents (such as residential house fire or commercial fire); or

(II) in the case of a firefighter who is unable to provide information on such number and type, an estimate of such number and type based on the method developed under subsection (d)(2);

(v) a list of additional risk factors, including smoking or drug use, as determined relevant by the Secretary; and

(vi) Other physical examination and medical history information relevant to a cancer incidence study or general health of firefighters not available in existing cancer registries.

(C) Any additional information that is deemed necessary by the Secretary.

(2) ~~DIAGNOSES AND TREATMENT.~~—In carrying out the data collection for purposes of inclusion under the Firefighter Registry, with respect to diagnoses and treatment of firefighters diagnosed with cancer, the Secretary shall enable the Firefighter Registry to link to State-based cancer registries, for a purpose described by clause (vi) or (vii) of section

1 ~~399B(e)(2)(D)~~ of the Public Health Service Act (42
 2 U.S.C. 280e(e)(2)(D)), to obtain information on—

3 ~~(A)~~ administrative information, including
 4 date of diagnoses and source of information;
 5 and

6 ~~(B)~~ pathological data characterizing the
 7 cancer, including cancer site, state of disease
 8 (pursuant to Staging Guide), incidence, and
 9 type of treatment.

10 ~~(d) METHODS.—~~

11 ~~(1) IN GENERAL.—~~For the purposes described
 12 in subsection (b), the Secretary is authorized to in-
 13 corporate questions into public health surveys, ques-
 14 tionnaires, and other databases.

15 ~~(2) REQUIRED STRATEGY.—~~The Secretary shall
 16 develop a strategy, working in consultation with the
 17 stakeholders identified in subsection (c), to maximize
 18 participation in the Firefighter Registry established
 19 under this Act. At minimum, the strategy shall in-
 20 clude the following:

21 ~~(A)~~ Identified minimum participation tar-
 22 gets for volunteer, paid-on-call, and career fire-
 23 fighters.

24 ~~(B)~~ A strategy for increasing awareness of
 25 the Firefighter Registry and maximizing par-

1 participation among volunteer, paid-on-call, and ca-
2 reer firefighters to meet minimum participation
3 targets.

4 (C) Additional steps that may be required
5 to ensure the equitable representation of groups
6 identified in paragraph (5).

7 (D) Information on how the Secretary will
8 store data described in subsection (c)(1) and
9 provide links to relevant health information de-
10 scribed in subsection (c)(2).

11 (E) Working in consultation with the ex-
12 perts described in subsection (c), a reliable and
13 standardized method for estimating the number
14 of fire incidents attended by a firefighter as
15 well as the type of fire incident so attended in
16 the case such firefighter is unable to provide
17 such information.

18 (3) REPORT TO CONGRESS.—The Secretary
19 shall submit the strategy described in paragraph (2)
20 to the Committee on Energy and Commerce of the
21 House of Representatives and the Committee on
22 Health, Education, Labor, and Pensions of the Sen-
23 ate not later than 30 days after the date of the com-
24 pletion of the strategy.

1 (4) GUIDANCE FOR INCLUSION AND MAINTENANCE OF DATA ON FIREFIGHTERS.—The Secretary
2 shall develop, in consultation with the stakeholders
3 identified in subsection (c), and disseminate guidance to State health agencies, State departments of
4 homeland security, and volunteer, paid-on-call, combination, and career firefighting agencies that outlines the following:
5
6
7
8

9 (A) How new information about firefighters will be submitted to the Firefighter
10 Registry for inclusion.
11

12 (B) How information about firefighters will be maintained and updated in the Firefighter
13 Registry over time.
14

15 (C) A method for estimating the number of fire incidents attended by a firefighter as well
16 as the type of fire incident so attended in the case such firefighter is unable to provide such
17 information.
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19

20 (D) Further information, as deemed necessary by the Secretary.
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22 (5) ENSURING REPRESENTATION OF UNDERREPRESENTED GROUPS IN REGISTRY.—In carrying
23 out this section, the Secretary shall take such measures as the Secretary deems appropriate to encour-
24
25

1 age the inclusion of data on minority, female, and
2 volunteer firefighters in the Firefighter Registry es-
3 tablished under this section.

4 (e) ~~CONSULTATION.~~—The Secretary shall, on a reg-
5 ular basis, seek feedback regarding the utility of the Fire-
6 fighter Registry established under this section and ways
7 the Firefighter Registry can be improved from non-Fed-
8 eral experts in the following areas:

9 (1) Public health experts with experience in de-
10 veloping and maintaining cancer registries.

11 (2) Epidemiologists with experience in studying
12 cancer incidence.

13 (3) Clinicians with experience in diagnosing and
14 treating cancer incidence.

15 (4) Active and retired volunteer, paid-on-call,
16 and career firefighters as well as relevant national
17 fire and emergency response organizations.

18 (f) ~~RESEARCH AVAILABILITY.~~—The Secretary shall
19 develop and make public a process for de-identifying data
20 from the Firefighter Registry and making such data avail-
21 able without a fee for research or other purposes. Such
22 process shall provide that such data shall be made avail-
23 able for such research purposes only if there is an agree-
24 ment to make findings, journal articles, or other print or
25 web-based publications derived from such research public

1 or available to the relevant stakeholders identified in sub-
 2 section (e).

3 ~~(g) PRIVACY.—In carrying out this Act, the Secretary~~
 4 ~~shall apply to the Firefighter Registry developed under~~
 5 ~~subsection (a) data security provisions and privacy stand-~~
 6 ~~ards that comply with the best practices of the Centers~~
 7 ~~for Disease Control and Prevention and provide for data~~
 8 ~~privacy and security standards similar to those in the~~
 9 ~~HIPAA privacy regulation, as defined in section~~
 10 ~~1180(b)(3) of the Social Security Act (42 U.S.C. 1320d-~~
 11 ~~9(b)(3)).~~

12 ~~(h) AUTHORIZATION OF FUNDS.—To carry out this~~
 13 ~~section, there are authorized to be appropriated~~
 14 ~~\$2,500,000 for each of the fiscal years 2018 through~~
 15 ~~2022.~~

16 **SECTION 1. SHORT TITLE.**

17 *This Act may be cited as the “Firefighter Cancer Reg-*
 18 *istry Act of 2018”.*

19 **SEC. 2. VOLUNTARY REGISTRY FOR FIREFIGHTER CANCER**
 20 **INCIDENCE.**

21 *(a) IN GENERAL.—The Secretary of Health and*
 22 *Human Services (referred to in this section as the “Sec-*
 23 *retary”), acting through the Director of the Centers for Dis-*
 24 *ease Control and Prevention and in coordination with other*
 25 *agencies as the Secretary determines appropriate, shall de-*

1 *velop and maintain, directly or through a grant or coopera-*
 2 *tive agreement, a voluntary registry of firefighters (referred*
 3 *to in this section as the “Firefighter Registry”) to collect*
 4 *relevant health and occupational information of such fire-*
 5 *fighters for purposes of determining cancer incidence.*

6 *(b) USE OF FIREFIGHTER REGISTRY.—The Firefighter*
 7 *Registry may be used for the following purposes:*

8 *(1) To improve data collection and data coordi-*
 9 *nation activities related to the nationwide monitoring*
 10 *of the incidence of cancer among firefighters.*

11 *(2) To collect, consolidate, and maintain, con-*
 12 *sistent with subsection (g), epidemiological informa-*
 13 *tion and analyses related to cancer incidence and*
 14 *trends among firefighters*

15 *(c) RELEVANT DATA.—*

16 *(1) DATA COLLECTION.—In carrying out the vol-*
 17 *untary data collection for purposes of inclusion under*
 18 *the Firefighter Registry, the Secretary may collect the*
 19 *following:*

20 *(A) Information, as determined by the Sec-*
 21 *retary under subsection (d)(1), of volunteer,*
 22 *paid-on-call, and career firefighters, independent*
 23 *of cancer status or diagnosis.*

24 *(B) Individual risk factors and occupa-*
 25 *tional history of firefighters.*

1 (C) Information, if available, related to—

2 (i) basic demographic information, in-
3 cluding—

4 (I) the age of the firefighter in-
5 volved during the relevant dates of oc-
6 cupation as a firefighter; and

7 (II) the age of cancer diagnosis;

8 (ii) the status of the firefighter as ei-
9 ther volunteer, paid-on-call, or career fire-
10 fighter;

11 (iii) the total number of years of occu-
12 pation as a firefighter and a detailing of
13 additional employment experience, whether
14 concurrent, before, or anytime thereafter;

15 (iv)(I) the approximate number of fire
16 incidents attended, including information
17 related to the type of fire incidents and the
18 role of the firefighter in responding to the
19 incident; or

20 (II) in the case of a firefighter for
21 whom information on such number and
22 type is unavailable, an estimate of such
23 number and type based on the method devel-
24 oped under subsection (d)(1)(D); and

1 (v) *other medical information and*
 2 *health history, including additional risk*
 3 *factors, as appropriate, and other informa-*
 4 *tion relevant to a cancer incidence study of*
 5 *firefighters.*

6 (2) *INFORMATION ON DIAGNOSES AND TREAT-*
 7 *MENT.—In carrying out paragraph (1), with respect*
 8 *to diagnoses and treatment of firefighters with cancer,*
 9 *the Secretary shall, as appropriate, enable the Fire-*
 10 *fighter Registry to electronically connect to State-*
 11 *based cancer registries, for a purpose described by*
 12 *clause (vi) or (vii) of section 399B(c)(2)(D) of the*
 13 *Public Health Service Act (42 U.S.C. 280e(c)(2)(D)),*
 14 *to obtain—*

15 (A) *date of diagnoses and source of informa-*
 16 *tion; and*

17 (B) *pathological data characterizing the*
 18 *cancer, including cancer site, state of disease*
 19 *(pursuant to Staging Guide), incidence, and*
 20 *type of treatment.*

21 (d) *FIREFIGHTER REGISTRY COORDINATION STRAT-*
 22 *EGY.—*

23 (1) *REQUIRED STRATEGY.—The Secretary shall,*
 24 *in consultation with the relevant stakeholders, such as*
 25 *medical professionals and public health experts with*

1 *experience developing and maintaining cancer reg-*
2 *istries, studying cancer incidence, or diagnosing and*
3 *treating cancer, including epidemiologists and pa-*
4 *thologists, develop a strategy to coordinate data collec-*
5 *tion activities, including within existing State reg-*
6 *istries, for inclusion in the Firefighter Registry estab-*
7 *lished under this Act. The strategy may include the*
8 *following:*

9 *(A) Increasing awareness of the Firefighter*
10 *Registry and encouraging participation among*
11 *volunteer, paid-on-call, and career firefighters.*

12 *(B) Consideration of unique data collection*
13 *needs that may arise to generate a statistically*
14 *reliable representation of minority, female, and*
15 *volunteer firefighters, including methods, as*
16 *needed, to encourage participation from such*
17 *populations.*

18 *(C) Information on how the Secretary will*
19 *store data described in subsection (c)(1) and pro-*
20 *vide electronic access to relevant health informa-*
21 *tion described in subsection (c)(2).*

22 *(D) Working in consultation with the ex-*
23 *perts described in subsection (e), a reliable and*
24 *standardized method for estimating the number*
25 *of fire incidents attended by a firefighter as well*

1 *as the type of fire incident so attended in the*
2 *case such firefighter is unable to provide such in-*
3 *formation.*

4 (2) *REPORT TO CONGRESS.—The Secretary shall*
5 *submit the strategy described in paragraph (1) to the*
6 *Committee on Energy and Commerce of the House of*
7 *Representatives and the Committee on Health, Edu-*
8 *cation, Labor, and Pensions of the Senate not later*
9 *than 30 days after the date of the completion of the*
10 *strategy.*

11 (3) *GUIDANCE FOR INCLUSION AND MAINTEN-*
12 *NANCE OF DATA ON FIREFIGHTERS.—The Secretary*
13 *shall develop, in consultation with the stakeholders*
14 *identified in subsection (e), State health agencies,*
15 *State departments of homeland security, and volun-*
16 *teer, paid-on-call, combination, and career fire-*
17 *fighting agencies, a strategy for inclusion of fire-*
18 *fighters in the registry that are representative of the*
19 *general population of firefighters, that outlines the fol-*
20 *lowing:*

21 (A) *How new information about firefighters*
22 *will be submitted to the Firefighter Registry for*
23 *inclusion.*

1 (B) *How information about firefighters will*
2 *be maintained and updated in the Firefighter*
3 *Registry over time.*

4 (C) *A method for estimating the number of*
5 *fire incidents attended by a firefighter as well as*
6 *the type of fire incident so attended in the case*
7 *such firefighter is unable to provide such infor-*
8 *mation.*

9 (D) *Further information, as deemed nec-*
10 *essary by the Secretary.*

11 (e) *CONSULTATION AND REPORT.—The Secretary shall*
12 *consult with non-Federal experts on the Firefighter Registry*
13 *established under this section, and shall submit to the Com-*
14 *mittee on Health, Education, Labor, and Pensions of the*
15 *Senate and the Committee on Energy and Commerce of the*
16 *House of Representatives a report that includes, as appro-*
17 *priate, information on goals achieved and improvements*
18 *needed to strengthen the Firefighter Registry. Such non-*
19 *Federal experts shall include the following:*

20 (1) *Public health experts with experience in de-*
21 *veloping and maintaining cancer registries.*

22 (2) *Epidemiologists with experience in studying*
23 *cancer incidence.*

24 (3) *Clinicians with experience in diagnosing and*
25 *treating cancer incidence.*

1 (4) *Active and retired volunteer, paid-on-call,*
2 *and career firefighters as well as relevant national*
3 *fire and emergency response organizations.*

4 (f) *RESEARCH AVAILABILITY.—Subject to subsection*
5 *(g), the Secretary shall ensure that information and anal-*
6 *ysis in the Firefighter Registry are available, as appro-*
7 *priate, to the public, including researchers and firefighters.*

8 (g) *PRIVACY.—In carrying out this Act, the Secretary*
9 *shall ensure that information in and analysis of the Fire-*
10 *fighter Registry are made available in a manner that, at*
11 *a minimum, protects personal privacy to the extent re-*
12 *quired by applicable Federal and State privacy law.*

13 (h) *AUTHORIZATION OF FUNDS.—To carry out this*
14 *section, there are authorized to be appropriated \$2,500,000*
15 *for each of the fiscal years 2018 through 2022.*

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S. 382

A BILL

To require the Secretary of Health and Human Services to develop a voluntary registry to collect data on cancer incidence among firefighters.

APRIL 25, 2018

Reported with an amendment