

115TH CONGRESS
1ST 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, and Mr. TESTER) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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”.

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

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

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

14 (1) To establish and improve collection infra-
15 structure and activities related to the nationwide
16 monitoring of the incidence of cancer among fire-
17 fighters.

18 (2) To collect, consolidate, store, and make
19 publicly available epidemiological information related
20 to cancer incidence and trends among firefighters.

21 (c) RELEVANT DATA.—

22 (1) IN GENERAL.—In carrying out the vol-
23 untary data collection for purposes of inclusion
24 under the Firefighter Registry, the Secretary should
25 seek to include the following information:

1 (A) Identifiable information from a rep-
2 resentative sample size, as determined by the
3 Secretary under subsection (d)(2)(A), of volun-
4 teer, paid-on-call, and career firefighters, inde-
5 pendent of cancer status or diagnosis.

6 (B) With respect to individual risk factors
7 and work history of firefighters, available infor-
8 mation on—

9 (i) basic demographic information, in-
10 cluding the age of the firefighter involved;

11 (ii) a listing of status of the fire-
12 fighter as either volunteer, paid-on-call, or
13 career firefighter;

14 (iii) the number of years on the job
15 and a detailing of additional employment
16 experience that was either performed con-
17 currently alongside firefighting service, be-
18 fore, or anytime thereafter;

19 (iv)(I) a measure of the number of
20 fire incidents attended as well as the type
21 of fire incidents (such as residential house
22 fire or commercial fire); or

23 (II) in the case of a firefighter who is
24 unable to provide information on such
25 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 399B(c)(2)(D) of the Public Health Service Act (42 U.S.C. 280e(c)(2)(D)), to obtain information on—

(A) administrative information, including date of diagnoses and source of information; and

1 (B) pathological data characterizing the
2 cancer, including cancer site, state of disease
3 (pursuant to Staging Guide), incidence, and
4 type of treatment.

5 (d) METHODS.—

6 (1) IN GENERAL.—For the purposes described
7 in subsection (b), the Secretary is authorized to in-
8 corporate questions into public health surveys, ques-
9 tionnaires, and other databases.

10 (2) REQUIRED STRATEGY.—The Secretary shall
11 develop a strategy, working in consultation with the
12 stakeholders identified in subsection (e), to maximize
13 participation in the Firefighter Registry established
14 under this Act. At minimum, the strategy shall in-
15 clude the following:

16 (A) Identified minimum participation tar-
17 gets for volunteer, paid-on-call, and career fire-
18 fighters.

19 (B) A strategy for increasing awareness of
20 the Firefighter Registry and maximizing par-
21 ticipation among volunteer, paid-on-call, and ca-
22 reer firefighters to meet minimum participation
23 targets.

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

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

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

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

22 (4) GUIDANCE FOR INCLUSION AND MAINTENANCE OF DATA ON FIREFIGHTERS.—The Secretary
23 shall develop, in consultation with the stakeholders
24 identified in subsection (e), and disseminate guid-
25

1 ance to State health agencies, State departments of
2 homeland security, and volunteer, paid-on-call, com-
3 bination, and career firefighting agencies that out-
4 lines the following:

5 (A) How new information about fire-
6 fighters will be submitted to the Firefighter
7 Registry for inclusion.

8 (B) How information about firefighters will
9 be maintained and updated in the Firefighter
10 Registry over time.

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

16 (D) Further information, as deemed nec-
17 essary by the Secretary.

18 (5) ENSURING REPRESENTATION OF UNDER-
19 REPRESENTED GROUPS IN REGISTRY.—In carrying
20 out this section, the Secretary shall take such meas-
21 ures as the Secretary deems appropriate to encour-
22 age the inclusion of data on minority, female, and
23 volunteer firefighters in the Firefighter Registry es-
24 tablished under this section.

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

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

8 (2) Epidemiologists with experience in studying
9 cancer incidence.

10 (3) Clinicians with experience in diagnosing and
11 treating cancer incidence.

12 (4) Active and retired volunteer, paid-on-call,
13 and career firefighters as well as relevant national
14 fire and emergency response organizations.

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

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

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

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