

115TH CONGRESS
1ST SESSION

H. R. 931

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 7, 2017

Mr. COLLINS of New York (for himself, Mr. PASCRELL, Mr. AMODEI, Mr. BARLETTA, Mr. BARR, Mr. BLUMENAUER, Ms. BONAMICI, Mr. BOST, Mrs. BROOKS of Indiana, Ms. BROWNLEY of California, Mrs. BUSTOS, Mrs. COMSTOCK, Mr. CONNOLLY, Mr. DEFazio, Ms. DEGETTE, Mr. DONOVAN, Mr. ELLISON, Mr. ENGEL, Ms. ESTY, Mr. FOSTER, Mr. FASO, Mr. GARAMENDI, Mr. GRIJALVA, Mr. HECK, Mr. JOYCE of Ohio, Ms. KAPTUR, Mr. KATKO, Mr. KILMER, Mr. KIND, Mr. KING of New York, Mr. KNIGHT, Ms. KUSTER of New Hampshire, Mr. LEVIN, Mr. LIPINSKI, Mr. LOBIONDO, Mr. LOEBSACK, Mrs. CAROLYN B. MALONEY of New York, Ms. MCCOLLUM, Mr. MCGOVERN, Mr. MEEHAN, Mr. MOULTON, Mr. NADLER, Mr. NOLAN, Mr. NORCROSS, Ms. NORTON, Mr. PAYNE, Mr. PERLMUTTER, Mr. PETERSON, Ms. PINGREE, Mr. POLIQUIN, Mr. RENACCI, Miss RICE of New York, Mr. ROGERS of Kentucky, Mr. RYAN of Ohio, Mr. SERRANO, Ms. SHEA-PORTER, Mr. SHUSTER, Ms. SINEMA, Mr. SIRES, Ms. SLAUGHTER, Mr. SMITH of New Jersey, Mr. SWALWELL of California, Ms. TENNEY, Mr. TONKO, Ms. TSONGAS, Mr. VALADAO, Mrs. WALORSKI, Mr. WALZ, Ms. WASSERMAN SCHULTZ, Mrs. WATSON COLEMAN, Mr. YARMUTH, Mr. YOUNG of Alaska, Mr. ZELDIN, Mr. LANCE, Mr. SMITH of Washington, Mr. SEAN PATRICK MALONEY of New York, Mr. QUIGLEY, Mr. GOTTHEIMER, and Ms. STEFANIK) introduced the following bill; which was referred to the Committee on Energy and Commerce

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

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

3 (II) in the case of a firefighter who is
4 unable to provide information on such
5 number and type, an estimate of such
6 number and type based on the method de-
7 veloped under subsection (d)(2);

8 (v) a list of additional risk factors, in-
9 cluding smoking or drug use, as deter-
10 mined relevant by the Secretary; and

11 (vi) other physical examination and
12 medical history information relevant to a
13 cancer incidence study or general health of
14 firefighters not available in existing cancer
15 registries.

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

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

1 399B(c)(2)(D) of the Public Health Service Act (42
2 U.S.C. 280e(c)(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 (e), 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 ticipation 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 (e), 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 (e), 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:
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9 (A) How new information about firefighters will be submitted to the Firefighter
10 Registry for inclusion.
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12 (B) How information about firefighters will be maintained and updated in the Firefighter
13 Registry over time.
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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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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-
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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.

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