

Committee Print

[SHOWING THE TEXT OF H.R. 931 AS FORWARDED BY THE SUBCOMMITTEE
ON HEALTH ON JUNE 29, 2017]

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. POPULATION-BASED REGISTRY FOR FIREFIGHTER**
7 **CANCER INCIDENCE.**

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

1 monitoring of the incidence of cancer among fire-
2 fighters.

3 (2) To collect, consolidate, store, and make
4 publicly available epidemiological information related
5 to cancer incidence and trends among firefighters.

6 (c) RELEVANT DATA.—

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

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

16 (B) With respect to individual risk factors
17 and work history of firefighters, available infor-
18 mation on—

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

21 (ii) a listing of status of the fire-
22 fighter as either volunteer, paid-on-call, or
23 career firefighter;

24 (iii) the number of years on the job
25 and a detailing of additional employment

1 experience that was either performed con-
2 currently alongside firefighting service, be-
3 fore, or anytime thereafter;

4 (iv)(I) a measure of the number of
5 fire incidents attended as well as the type
6 of fire incidents (such as residential house
7 fire or commercial fire); or

8 (II) in the case of a firefighter for
9 whom information on such number and
10 type is not available, an estimate of such
11 number and type based on the method de-
12 veloped under subsection (d)(2);

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

16 (vi) other physical examination and
17 medical history information relevant to a
18 cancer incidence study or general health of
19 firefighters not available in existing cancer
20 registries.

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

23 (2) DIAGNOSES AND TREATMENT.—In carrying
24 out the data collection for purposes of inclusion
25 under the Firefighter Registry, with respect to diag-

1 noses and treatment of firefighters diagnosed with
2 cancer, the Secretary shall enable the Firefighter
3 Registry to link to State-based cancer registries, for
4 a purpose described by clause (vi) or (vii) of section
5 399B(c)(2)(D) of the Public Health Service Act (42
6 U.S.C. 280e(c)(2)(D)), to obtain information on—

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

10 (B) pathological data characterizing the
11 cancer, including cancer site, state of disease
12 (pursuant to Staging Guide), incidence, and
13 type of treatment.

14 (d) METHODS.—

15 (1) IN GENERAL.—For the purposes described
16 in subsection (b), the Secretary is authorized to in-
17 corporate questions into public health surveys, ques-
18 tionnaires, and other databases.

19 (2) REQUIRED STRATEGY.—The Secretary shall
20 develop a strategy, working in consultation with the
21 stakeholders identified in subsection (e), to maximize
22 participation in the Firefighter Registry established
23 under this Act. At minimum, the strategy shall in-
24 clude the following:

1 (A) Identified minimum participation tar-
2 gets for volunteer, paid-on-call, and career fire-
3 fighters.

4 (B) A strategy for increasing awareness of
5 the Firefighter Registry and maximizing par-
6 ticipation among volunteer, paid-on-call, and ca-
7 reer firefighters to meet minimum participation
8 targets.

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

12 (D) Information on how the Secretary will
13 store data described in subsection (c)(1) and
14 provide links to relevant health information de-
15 scribed in subsection (c)(2).

16 (E) Working in consultation with the ex-
17 perts described in subsection (e), a reliable and
18 standardized method for estimating the number
19 of fire incidents attended by a firefighter as
20 well as the type of fire incident so attended in
21 the case such firefighter is unable to provide
22 such information.

23 (3) REPORT TO CONGRESS.—The Secretary
24 shall submit the strategy described in paragraph (2)
25 to the Committee on Energy and Commerce of the

1 House of Representatives and the Committee on
2 Health, Education, Labor, and Pensions of the Sen-
3 ate not later than 30 days after the date of the com-
4 pletion of the strategy.

5 (4) GUIDANCE FOR INCLUSION AND MAINTEN-
6 NANCE OF DATA ON FIREFIGHTERS.—The Secretary
7 shall develop, in consultation with the stakeholders
8 identified in subsection (e), State health agencies,
9 State departments of homeland security, and volun-
10 teer, paid-on-call, combination, and career fire-
11 fighting agencies, a strategy for inclusion of fire-
12 fighters in the registry that are representative of the
13 general population of firefighters, that outlines the
14 following:

15 (A) How new information about fire-
16 fighters will be submitted to the Firefighter
17 Registry for inclusion.

18 (B) How information about firefighters will
19 be maintained and updated in the Firefighter
20 Registry over time.

21 (C) A method for estimating the number of
22 fire incidents attended by a firefighter as well
23 as the type of fire incident so attended in the
24 case such firefighter is unable to provide such
25 information.

1 (D) Further information, as deemed nec-
2 essary by the Secretary.

3 (5) ENSURING REPRESENTATION OF UNDER-
4 REPRESENTED GROUPS IN REGISTRY.—In carrying
5 out this section, the Secretary shall take such meas-
6 ures as the Secretary deems appropriate to encour-
7 age the inclusion of data on minority, female, and
8 volunteer firefighters in the Firefighter Registry es-
9 tablished under this section.

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

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

17 (2) Epidemiologists with experience in studying
18 cancer incidence.

19 (3) Clinicians with experience in diagnosing and
20 treating cancer incidence.

21 (4) Active and retired volunteer, paid-on-call,
22 and career firefighters as well as relevant national
23 fire and emergency response organizations.

24 (f) RESEARCH AVAILABILITY.—The Secretary shall
25 develop and make public a process for de-identifying data

1 from the Firefighter Registry and making such data avail-
2 able without a fee for research or other purposes. Such
3 process shall provide that such data shall be made avail-
4 able for such research purposes only if there is an agree-
5 ment to make findings, journal articles, or other print or
6 web-based publications derived from such research public
7 or available to the relevant stakeholders identified in sub-
8 section (e).

9 (g) PRIVACY.—In carrying out this Act, the Secretary
10 shall apply to the Firefighter Registry developed under
11 subsection (a) data security provisions and privacy stand-
12 ards that comply with the best practices of the Centers
13 for Disease Control and Prevention and provide for data
14 privacy and security standards similar to those in the
15 HIPAA privacy regulation, as defined in section
16 1180(b)(3) of the Social Security Act (42 U.S.C. 1320d-
17 9(b)(3)).

18 (h) AUTHORIZATION OF FUNDS.—To carry out this
19 section, there are authorized to be appropriated
20 \$2,500,000 for each of the fiscal years 2018 through
21 2022.