

Union Calendar No. 215

115TH CONGRESS
1ST SESSION

H. R. 931

[Report No. 115-301]

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

SEPTEMBER 8, 2017

Additional sponsors: Mr. REED, Ms. VELÁZQUEZ, Mr. MACARTHUR, Mr. CURBELO of Florida, Mr. FRELINGHUYSEN, Mr. LANGEVIN, Mr. LYNCH, Mr. SCOTT of Virginia, Mr. COSTELLO of Pennsylvania, Mr. FITZPATRICK, Ms. DELAURO, Mr. MURPHY of Pennsylvania, Ms. DELBENE, Mr. RASKIN, Mr. JONES, Mr. YOUNG of Iowa, Mr. KELLY of Pennsylvania, Ms. SPEIER, Ms. ROSEN, Mr. MCKINLEY, Mr. BROWN of Maryland, Mr. WITTMAN, Mr. TURNER, Mr. STEWART, Mr. HOYER, Mr. CICILLINE, Mr. GENE GREEN of Texas, Mr. MARSHALL, Mr. DESAULNIER, Ms. LOFGREN, Mrs. DEMINGS, Mr. TAKANO, Mr. TAYLOR, Ms. ROS-LEHTINEN, Mr. CARBAJAL, Mrs. LOVE, Mr. LARSON of Connecticut, Mr. BISHOP of Utah, Mr. CLAY, Mr. REICHERT, Mr. SCHNEIDER, Mr. RUPPERSBERGER, Mr. GUTHRIE, Mr. STIVERS, Mr. BRADY of Pennsylvania, Mr. GALLEGRO, Mr. COMER, Mr. GARRETT, Mr. SARBANES, Mr. DELANEY, Mr. GRAVES of Missouri, Mr. HUFFMAN, Mr. CARSON of Indiana, Mr. HIGGINS of New York, Mr. CAPUANO, Mr. THOMPSON of Pennsylvania, Mr. CONYERS, Mr. JENKINS of West Virginia, Ms. BORDALLO, Mr. O'HALLERAN, Mr. MCEACHIN, Mr. PETERS, Mr. CÁRDENAS, Ms. ESHOO, Mr. LATTA, Mr. TIPTON, Ms. MATSUI, Mrs. MURPHY of Florida, Mr. HUDSON, Mr. DENT, Mr. KENNEDY, Ms. HERRERA BEUTLER, Mr. LOWENTHAL, Ms. MCSALLY, Mr. BRENDAN F. BOYLE of Pennsylvania, Mr. MITCHELL, Mr. SOTO, Mr. GALLAGHER, Ms. SCHAKOWSKY, Mr. LAWSON of Florida, Mr. UPTON, Mr. GRIFFITH, Mr. VISCLOSKY, Mr. JOHNSON of Ohio, Ms. WILSON of Florida, Mr. COFFMAN, Mr. COURTNEY, Mr. GONZALEZ of Texas, Mrs. MCMORRIS RODGERS, Mr. POLIS, Mrs. NAPOLITANO, Ms. MENG, Mr. SMUCKER, Ms. FRANKEL of Florida, Ms. CLARKE of New York, Mr. GOSAR, Ms. MOORE, Mr. SESSIONS, Ms. HANABUSA, Mr. KHANNA, Mr. ISSA, Mr. POE of Texas, Mr. CORREA, Mr. KEATING, Mr. EMMER, Mr. BEN RAY LUJÁN of New Mexico, Ms. JUDY CHU of California, Mr. CALVERT, Mr. HOLLINGSWORTH, and Mr. EVANS

SEPTEMBER 8, 2017

Reported with an amendment, committed to the Committee of the Whole
House on the State of the Union, and ordered to be printed

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

[For text of introduced bill, see copy of bill as introduced on February 7, 2017]

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 Reg-*
5 *istry 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 Centers*
10 *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 this*
13 *section as the “Firefighter Registry”) to collect relevant his-*
14 *tory and occupational information of such firefighters that*
15 *can be linked to available cancer registry data collected by*
16 *existing State cancer registries.*

17 *(b) USE OF FIREFIGHTER REGISTRY.—The Firefighter*
18 *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 pub-*
24 *licly available epidemiological information related to*
25 *cancer incidence and trends among firefighters.*

1 (c) *RELEVANT DATA.*—

2 (1) *IN GENERAL.*—*In carrying out the voluntary*
3 *data collection for purposes of inclusion under the*
4 *Firefighter Registry, the Secretary should seek to in-*
5 *clude 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 firefighter*
17 *as either volunteer, paid-on-call, or career*
18 *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 fire*
25 *incidents attended as well as the type of fire*

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

3 (II) in the case of a firefighter for
4 whom information on such number and
5 type is not available, an estimate of such
6 number and type based on the method devel-
7 oped under subsection (d)(2);

8 (v) a list of additional risk factors, in-
9 cluding smoking or drug use, as determined
10 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 under
20 the Firefighter Registry, with respect to diagnoses and
21 treatment of firefighters diagnosed with cancer, the
22 Secretary shall enable the Firefighter Registry to link
23 to State-based cancer registries, for a purpose de-
24 scribed by clause (vi) or (vii) of section 399B(c)(2)(D)

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

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

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

9 *(d) METHODS.—*

10 *(1) IN GENERAL.—For the purposes described in*
11 *subsection (b), the Secretary is authorized to incor-*
12 *porate questions into public health surveys, question-*
13 *naires, and other databases.*

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

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

23 *(B) A strategy for increasing awareness of*
24 *the Firefighter Registry and maximizing partici-*
25 *pation among volunteer, paid-on-call, and career*

1 *firefighters to meet minimum participation tar-*
2 *gets.*

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

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

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

17 *(3) REPORT TO CONGRESS.—The Secretary shall*
18 *submit the strategy described in paragraph (2) to the*
19 *Committee on Energy and Commerce of the House of*
20 *Representatives and the Committee on Health, Edu-*
21 *cation, Labor, and Pensions of the Senate not later*
22 *than 30 days after the date of the completion of the*
23 *strategy.*

24 *(4) GUIDANCE FOR INCLUSION AND MAINTEN-*
25 *NANCE OF DATA ON FIREFIGHTERS.—The Secretary*

1 shall develop, in consultation with the stakeholders
2 identified in subsection (e), State health agencies,
3 State departments of homeland security, and volun-
4 teer, paid-on-call, combination, and career fire-
5 fighting agencies, a strategy for inclusion of fire-
6 fighters in the registry that are representative of the
7 general population of firefighters, that outlines the fol-
8 lowing:

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

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

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

20 (D) Further information, as deemed nec-
21 essary by the Secretary.

22 (5) ENSURING REPRESENTATION OF UNDERREP-
23 RESENTED GROUPS IN REGISTRY.—In carrying out
24 this section, the Secretary shall take such measures as
25 the Secretary deems appropriate to encourage the in-

1 *clusion of data on minority, female, and volunteer*
2 *firefighters in the Firefighter Registry established*
3 *under this section.*

4 *(e) CONSULTATION.—The Secretary shall, on a regular*
5 *basis, seek feedback regarding the utility of the Firefighter*
6 *Registry established under this section and ways the Fire-*
7 *fighter Registry can be improved from non-Federal experts*
8 *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 de-*
19 *velop 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 proc-*
22 *ess shall provide that such data shall be made available for*
23 *such research purposes only if there is an agreement to*
24 *make findings, journal articles, or other print or web-based*

1 *publications derived from such research public or available*
2 *to the relevant stakeholders identified in subsection (e).*

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

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

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