

**Suspend the Rules and Pass the Bill, H.R. 931, with an Amendment**

**(The amendment strikes all after the enacting clause and inserts a new text)**

115<sup>TH</sup> CONGRESS  
1<sup>ST</sup> 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.

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## 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



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 \$2,000,000 for each of the fiscal years 2018 through  
21 2022.

22 **SEC. 3. CUT-GO COMPLIANCE.**

23 Subsection (f) of section 319D of the Public Health  
24 Service Act (42 U.S.C. 247d-4) is amended by striking

- 1 “through 2018” and inserting “through 2017, and
- 2 \$128,300,000 for fiscal year 2018”.