

AMENDMENT NO. _____ Calendar No. _____

Purpose: In the nature of a substitute.

IN THE SENATE OF THE UNITED STATES—115th Cong., 2d Sess.

S. 382

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

Referred to the Committee on _____ and
ordered to be printed

Ordered to lie on the table and to be printed

AMENDMENT IN THE NATURE OF A SUBSTITUTE intended
to be proposed by _____

Viz:

1 Strike all after the enacting clause and insert the fol-
2 lowing:

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Firefighter Cancer
5 Registry Act of 2018”.

6 **SEC. 2. VOLUNTARY REGISTRY FOR FIREFIGHTER CANCER**
7 **INCIDENCE.**

8 (a) IN GENERAL.—The Secretary of Health and
9 Human Services (referred to in this section as the “Sec-
10 retary”), acting through the Director of the Centers for
11 Disease Control and Prevention and in coordination with

1 other agencies as the Secretary determines appropriate,
2 shall develop and maintain, directly or through a grant
3 or cooperative agreement, a voluntary registry of fire-
4 fighters (referred to in this section as the “Firefighter
5 Registry”) to collect relevant health and occupational in-
6 formation of such firefighters for purposes of determining
7 cancer incidence.

8 (b) USE OF FIREFIGHTER REGISTRY.—The Fire-
9 fighter Registry may be used for the following purposes:

10 (1) To improve data collection and data coordi-
11 nation activities related to the nationwide monitoring
12 of the incidence of cancer among firefighters.

13 (2) To collect, consolidate, and maintain, con-
14 sistent with subsection (g), epidemiological informa-
15 tion and analyses related to cancer incidence and
16 trends among firefighters

17 (c) RELEVANT DATA.—

18 (1) DATA COLLECTION.—In carrying out the
19 voluntary data collection for purposes of inclusion
20 under the Firefighter Registry, the Secretary may
21 collect the following:

22 (A) Information, as determined by the Sec-
23 retary under subsection (d)(1), of volunteer,
24 paid-on-call, and career firefighters, inde-
25 pendent of cancer status or diagnosis.

1 (B) Individual risk factors and occupa-
2 tional history of firefighters.

3 (C) Information, if available, related to—

4 (i) basic demographic information, in-
5 cluding—

6 (I) the age of the firefighter in-
7 volved during the relevant dates of oc-
8 cupation as a firefighter; and

9 (II) the age of cancer diagnosis;
10 (ii) the status of the firefighter as ei-
11 ther volunteer, paid-on-call, or career fire-
12 fighter;

13 (iii) the total number of years of occu-
14 pation as a firefighter and a detailing of
15 additional employment experience, whether
16 concurrent, before, or anytime thereafter;

17 (iv)(I) the approximate number of fire
18 incidents attended, including information
19 related to the type of fire incidents and the
20 role of the firefighter in responding to the
21 incident; or

22 (II) in the case of a firefighter for
23 whom information on such number and
24 type is unavailable, an estimate of such

1 number and type based on the method de-
2 veloped under subsection (d)(1)(D); and
3 (v) other medical information and
4 health history, including additional risk
5 factors, as appropriate, and other informa-
6 tion relevant to a cancer incidence study of
7 firefighters.

8 (2) INFORMATION ON DIAGNOSES AND TREAT-
9 MENT.—In carrying out paragraph (1), with respect
10 to diagnoses and treatment of firefighters with can-
11 cer, the Secretary shall, as appropriate, enable the
12 Firefighter Registry to electronically connect to
13 State-based cancer registries, for a purpose de-
14 scribed by clause (vi) or (vii) of section
15 399B(c)(2)(D) of the Public Health Service Act (42
16 U.S.C. 280e(c)(2)(D)), to obtain—

17 (A) date of diagnoses and source of infor-
18 mation; and

19 (B) pathological data characterizing the
20 cancer, including cancer site, state of disease
21 (pursuant to Staging Guide), incidence, and
22 type of treatment.

23 (d) FIREFIGHTER REGISTRY COORDINATION STRAT-
24 EGY.—

1 (1) REQUIRED STRATEGY.—The Secretary
2 shall, in consultation with the relevant stakeholders,
3 such as medical professionals and public health ex-
4 perts with experience developing and maintaining
5 cancer registries, studying cancer incidence, or diag-
6 nosing and treating cancer, including epidemiologists
7 and pathologists, develop a strategy to coordinate
8 data collection activities, including within existing
9 State registries, for inclusion in the Firefighter Reg-
10 istry established under this Act. The strategy may
11 include the following:

12 (A) Increasing awareness of the Fire-
13 fighter Registry and encouraging participation
14 among volunteer, paid-on-call, and career fire-
15 fighters.

16 (B) Consideration of unique data collection
17 needs that may arise to generate a statistically
18 reliable representation of minority, female, and
19 volunteer firefighters, including methods, as
20 needed, to encourage participation from such
21 populations.

22 (C) Information on how the Secretary will
23 store data described in subsection (c)(1) and
24 provide electronic access to relevant health in-
25 formation described in subsection (c)(2).

1 (D) Working in consultation with the ex-
2 perts described in subsection (e), a reliable and
3 standardized method for estimating the number
4 of fire incidents attended by a firefighter as
5 well as the type of fire incident so attended in
6 the case such firefighter is unable to provide
7 such information.

8 (2) REPORT TO CONGRESS.—The Secretary
9 shall submit the strategy described in paragraph (1)
10 to the Committee on Energy and Commerce of the
11 House of Representatives and the Committee on
12 Health, Education, Labor, and Pensions of the Sen-
13 ate not later than 30 days after the date of the com-
14 pletion of the strategy.

15 (3) GUIDANCE FOR INCLUSION AND MAINTEN-
16 ANCE OF DATA ON FIREFIGHTERS.—The Secretary
17 shall develop, in consultation with the stakeholders
18 identified in subsection (e), State health agencies,
19 State departments of homeland security, and volun-
20 teer, paid-on-call, combination, and career fire-
21 fighting agencies, a strategy for inclusion of fire-
22 fighters in the registry that are representative of the
23 general population of firefighters, that outlines the
24 following:

1 (A) How new information about fire-
2 fighters will be submitted to the Firefighter
3 Registry for inclusion.

4 (B) How information about firefighters will
5 be maintained and updated in the Firefighter
6 Registry over time.

7 (C) A method for estimating the number of
8 fire incidents attended by a firefighter as well
9 as the type of fire incident so attended in the
10 case such firefighter is unable to provide such
11 information.

12 (D) Further information, as deemed nec-
13 essary by the Secretary.

14 (e) CONSULTATION AND REPORT.—The Secretary
15 shall consult with non-Federal experts on the Firefighter
16 Registry established under this section, and shall submit
17 to the Committee on Health, Education, Labor, and Pen-
18 sions of the Senate and the Committee on Energy and
19 Commerce of the House of Representatives a report that
20 includes, as appropriate, information on goals achieved
21 and improvements needed to strengthen the Firefighter
22 Registry. Such non-Federal experts shall include the fol-
23 lowing:

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

1 (2) Epidemiologists with experience in studying
2 cancer incidence.

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

5 (4) Active and retired volunteer, paid-on-call,
6 and career firefighters as well as relevant national
7 fire and emergency response organizations.

8 (f) RESEARCH AVAILABILITY.—Subject to subsection
9 (g), the Secretary shall ensure that information and anal-
10 ysis in the Firefighter Registry are available, as appro-
11 priate, to the public, including researchers and fire-
12 fighters.

13 (g) PRIVACY.—In carrying out this Act, the Secretary
14 shall ensure that information in and analysis of the Fire-
15 fighter Registry are made available in a manner that, at
16 a minimum, protects personal privacy to the extent re-
17 quired by applicable Federal and State privacy law.

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.