

115TH CONGRESS
1ST SESSION

S. _____

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

IN THE SENATE OF THE UNITED STATES

_____ introduced the following bill; which was read twice
and referred to the Committee on _____

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

1 maintain, directly or through a grant or cooperative agree-
2 ment, a voluntary registry of firefighters (referred to in
3 this section as the “Firefighter Registry”) to collect rel-
4 evant history and occupational information of such fire-
5 fighters that can be linked to available cancer registry
6 data collected by existing State cancer registries.

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

9 (1) To establish and improve collection infra-
10 structure and activities related to the nationwide
11 monitoring of the incidence of cancer among fire-
12 fighters.

13 (2) To collect, consolidate, store, and make
14 publicly available epidemiological information related
15 to cancer incidence and trends among firefighters.

16 (c) RELEVANT DATA.—

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

21 (A) Identifiable information from a rep-
22 resentative sample size, as determined by the
23 Secretary under subsection (d)(2)(A), of volun-
24 teer, paid-on-call, and career firefighters, inde-
25 pendent of cancer status or diagnosis.

1 (B) With respect to individual risk factors
2 and work history of firefighters, available infor-
3 mation on—

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

6 (ii) a listing of status of the fire-
7 fighter as either volunteer, paid-on-call, or
8 career firefighter;

9 (iii) the number of years on the job
10 and a detailing of additional employment
11 experience that was either performed con-
12 currently alongside firefighting service, be-
13 fore, or anytime thereafter;

14 (iv)(I) a measure of the number of
15 fire incidents attended as well as the type
16 of fire incidents (such as residential house
17 fire or commercial fire); or

18 (II) in the case of a firefighter who is
19 unable to provide information on such
20 number and type, an estimate of such
21 number and type based on the method de-
22 veloped under subsection (d)(2);

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

1 (vi) Other physical examination and
2 medical history information relevant to a
3 cancer incidence study or general health of
4 firefighters not available in existing cancer
5 registries.

6 (C) Any additional information that is
7 deemed necessary by the Secretary.

8 (2) DIAGNOSES AND TREATMENT.—In carrying
9 out the data collection for purposes of inclusion
10 under the Firefighter Registry, with respect to diag-
11 noses and treatment of firefighters diagnosed with
12 cancer, the Secretary shall enable the Firefighter
13 Registry to link to State-based cancer registries, for
14 a purpose described 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 information on—

17 (A) administrative information, including
18 date of diagnoses and source of information;
19 and

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

24 (d) METHODS.—

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

5 (2) REQUIRED STRATEGY.—The Secretary shall
6 develop a strategy, working in consultation with the
7 stakeholders identified in subsection (e), to maximize
8 participation in the Firefighter Registry established
9 under this Act. At minimum, the strategy shall in-
10 clude the following:

11 (A) Identified minimum participation tar-
12 gets for volunteer, paid-on-call, and career fire-
13 fighters.

14 (B) A strategy for increasing awareness of
15 the Firefighter Registry and maximizing par-
16 ticipation among volunteer, paid-on-call, and ca-
17 reer firefighters to meet minimum participation
18 targets.

19 (C) Additional steps that may be required
20 to ensure the equitable representation of groups
21 identified in paragraph (5).

22 (D) Information on how the Secretary will
23 store data described in subsection (c)(1) and
24 provide links to relevant health information de-
25 scribed in subsection (c)(2).

1 (E) 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 (3) REPORT TO CONGRESS.—The Secretary
9 shall submit the strategy described in paragraph (2)
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 (4) GUIDANCE FOR INCLUSION AND MAINTEN-
16 NANCE OF DATA ON FIREFIGHTERS.—The Secretary
17 shall develop, in consultation with the stakeholders
18 identified in subsection (e), and disseminate guid-
19 ance to State health agencies, State departments of
20 homeland security, and volunteer, paid-on-call, com-
21 bination, and career firefighting agencies that out-
22 lines the following:

23 (A) How new information about fire-
24 fighters will be submitted to the Firefighter
25 Registry for inclusion.

1 (B) How information about firefighters will
2 be maintained and updated in the Firefighter
3 Registry over time.

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

9 (D) Further information, as deemed nec-
10 essary by the Secretary.

11 (5) ENSURING REPRESENTATION OF UNDER-
12 REPRESENTED GROUPS IN REGISTRY.—In carrying
13 out this section, the Secretary shall take such meas-
14 ures as the Secretary deems appropriate to encour-
15 age the inclusion of data on minority, female, and
16 volunteer firefighters in the Firefighter Registry es-
17 tablished under this section.

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

23 (1) Public health experts with experience in de-
24 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.—The Secretary shall
9 develop and make public a process for de-identifying data
10 from the Firefighter Registry and making such data avail-
11 able without a fee for research or other purposes. Such
12 process shall provide that such data shall be made avail-
13 able for such research purposes only if there is an agree-
14 ment to make findings, journal articles, or other print or
15 web-based publications derived from such research public
16 or available to the relevant stakeholders identified in sub-
17 section (e).

18 (g) PRIVACY.—In carrying out this Act, the Secretary
19 shall apply to the Firefighter Registry developed under
20 subsection (a) data security provisions and privacy stand-
21 ards that comply with the best practices of the Centers
22 for Disease Control and Prevention and provide for data
23 privacy and security standards similar to those in the
24 HIPAA privacy regulation, as defined in section

1 1180(b)(3) of the Social Security Act (42 U.S.C. 1320d-
2 9(b)(3)).

3 (h) AUTHORIZATION OF FUNDS.—To carry out this
4 section, there are authorized to be appropriated
5 \$2,500,000 for each of the fiscal years 2018 through
6 2022.