

115TH CONGRESS
1ST SESSION

H. R. 931

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 13, 2017

Received; read twice and referred to the Committee on Health, Education,
Labor, and Pensions

AN ACT

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,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Firefighter Cancer
3 Registry Act of 2017”.

4 **SEC. 2. POPULATION-BASED REGISTRY FOR FIREFIGHTER**
5 **CANCER INCIDENCE.**

6 (a) IN GENERAL.—The Secretary of Health and
7 Human Services, acting through the Director of the Cen-
8 ters for Disease Control and Prevention, shall develop and
9 maintain, directly or through a grant or cooperative agree-
10 ment, a voluntary registry of firefighters (referred to in
11 this section as the “Firefighter Registry”) to collect rel-
12 evant history and occupational information of such fire-
13 fighters that can be linked to available cancer registry
14 data collected by existing State cancer registries.

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

17 (1) To establish and improve collection infra-
18 structure and activities related to the nationwide
19 monitoring of the incidence of cancer among fire-
20 fighters.

21 (2) To collect, consolidate, store, and make
22 publicly available epidemiological information related
23 to cancer incidence and trends among firefighters.

24 (c) RELEVANT DATA.—

25 (1) IN GENERAL.—In carrying out the vol-
26 untary data collection for purposes of inclusion

1 under the Firefighter Registry, the Secretary should
2 seek to include the following information:

3 (A) Identifiable information from a rep-
4 resentative sample size, as determined by the
5 Secretary under subsection (d)(2)(A), of volun-
6 teer, paid-on-call, and career firefighters, inde-
7 pendent of cancer status or diagnosis.

8 (B) With respect to individual risk factors
9 and work history of firefighters, available infor-
10 mation on—

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

13 (ii) a listing of status of the fire-
14 fighter as either volunteer, paid-on-call, or
15 career firefighter;

16 (iii) the number of years on the job
17 and a detailing of additional employment
18 experience that was either performed con-
19 currently alongside firefighting service, be-
20 fore, or anytime thereafter;

21 (iv)(I) a measure of the number of
22 fire incidents attended as well as the type
23 of fire incidents (such as residential house
24 fire or commercial fire); or

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

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

9 (vi) other physical examination and
10 medical history information relevant to a
11 cancer incidence study or general health of
12 firefighters not available in existing cancer
13 registries.

14 (C) Any additional information that is
15 deemed necessary by the Secretary.

16 (2) DIAGNOSES AND TREATMENT.—In carrying
17 out the data collection for purposes of inclusion
18 under the Firefighter Registry, with respect to diag-
19 noses and treatment of firefighters diagnosed with
20 cancer, the Secretary shall enable the Firefighter
21 Registry to link to State-based cancer registries, for
22 a purpose described by clause (vi) or (vii) of section
23 399B(c)(2)(D) of the Public Health Service Act (42
24 U.S.C. 280e(c)(2)(D)), to obtain information on—

1 (A) administrative information, including
2 date of diagnoses and source of information;
3 and

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

8 (d) METHODS.—

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

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

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

22 (B) A strategy for increasing awareness of
23 the Firefighter Registry and maximizing par-
24 ticipation among volunteer, paid-on-call, and ca-

1 reer firefighters to meet minimum participation
2 targets.

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
8 provide 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
14 well as the type of fire incident so attended in
15 the case such firefighter is unable to provide
16 such information.

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

24 (4) GUIDANCE FOR INCLUSION AND MAINTENANCE OF DATA ON FIREFIGHTERS.—The Secretary
25

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
8 following:

9 (A) How new information about fire-
10 fighters will be submitted to the Firefighter
11 Registry for 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
17 as the type of fire incident so attended in the
18 case such firefighter is unable to provide such
19 information.

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

22 (5) ENSURING REPRESENTATION OF UNDER-
23 REPRESENTED GROUPS IN REGISTRY.—In carrying
24 out this section, the Secretary shall take such meas-
25 ures as the Secretary deems appropriate to encour-

1 age the inclusion of data on minority, female, and
2 volunteer firefighters in the Firefighter Registry es-
3 tablished under this section.

4 (e) CONSULTATION.—The Secretary shall, on a reg-
5 ular basis, seek feedback regarding the utility of the Fire-
6 fighter Registry established under this section and ways
7 the Firefighter Registry can be improved from non-Fed-
8 eral experts 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
19 develop 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
22 process shall provide that such data shall be made avail-
23 able for such research purposes only if there is an agree-
24 ment to make findings, journal articles, or other print or
25 web-based publications derived from such research public

1 or available to the relevant stakeholders identified in sub-
2 section (e).

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

12 (h) AUTHORIZATION OF FUNDS.—To carry out this
13 section, there are authorized to be appropriated
14 \$2,000,000 for each of the fiscal years 2018 through
15 2022.

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

17 Subsection (f) of section 319D of the Public Health
18 Service Act (42 U.S.C. 247d-4) is amended by striking
19 “through 2018” and inserting “through 2017, and
20 \$128,300,000 for fiscal year 2018”.

Passed the House of Representatives September 12,
2017.

Attest:

KAREN L. HAAS,

Clerk.