

In the Senate of the United States,

May 10, 2018.

Resolved, That the bill from the House of Representatives (H.R. 931) entitled “An Act to require the Secretary of Health and Human Services to develop a voluntary registry to collect data on cancer incidence among firefighters.”, do pass with the following

AMENDMENT:

Strike all after the enacting clause and insert the following:

1 ***SECTION 1. SHORT TITLE.***

2 *This Act may be cited as the Firefighter Cancer Reg-*
3 *istry Act of 2018.*

4 ***SEC. 2. VOLUNTARY REGISTRY FOR FIREFIGHTER CANCER***
5 ***INCIDENCE.***

6 *(a) IN GENERAL.—The Secretary of Health and*
7 *Human Services (referred to in this section as the Sec-*
8 *retary), acting through the Director of the Centers for Dis-*
9 *ease Control and Prevention and in coordination with other*

1 agencies as the Secretary determines appropriate, shall de-
2 velop and maintain, directly or through a grant or coopera-
3 tive agreement, a voluntary registry of firefighters (referred
4 to in this section as the Firefighter Registry) to collect rel-
5 evant health and occupational information of such fire-
6 fighters for purposes of determining cancer incidence.

7 (b) *USE OF FIREFIGHTER REGISTRY.*—The Firefighter
8 Registry may be used for the following purposes:

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

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

16 (c) *RELEVANT DATA.*—

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

21 (A) *Information, as determined by the Sec-*
22 *retary under subsection (d)(1), of volunteer,*
23 *paid-on-call, and career firefighters, independent*
24 *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 devel-*
2 *oped 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 cancer,*
11 *the Secretary shall, as appropriate, enable the Fire-*
12 *fighter Registry to electronically connect to State-*
13 *based cancer registries, for a purpose described by*
14 *clause (vi) or (vii) of section 399B(c)(2)(D) of the*
15 *Public Health Service Act (42 U.S.C. 280e(c)(2)(D)),*
16 *to obtain—*

17 *(A) date of diagnoses and source of informa-*
18 *tion; 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 shall,*
2 *in consultation with the relevant stakeholders identi-*
3 *fied in subsection (e), including epidemiologists and*
4 *pathologists, develop a strategy to coordinate data col-*
5 *lection activities, including within existing State reg-*
6 *istries, for inclusion in the Firefighter Registry estab-*
7 *lished under this Act. The strategy may include the*
8 *following:*

9 (A) *Increasing awareness of the Firefighter*
10 *Registry and encouraging participation among*
11 *volunteer, paid-on-call, and career firefighters.*

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

18 (C) *Information on how the Secretary will*
19 *store data described in subsection (c)(1) and pro-*
20 *vide electronic access to relevant health informa-*
21 *tion described in subsection (c)(2).*

22 (D) *Working in consultation with the ex-*
23 *perts described in subsection (e), a reliable and*
24 *standardized method for estimating the number*
25 *of fire incidents attended by a firefighter as well*

1 *as the type of fire incident so attended in the*
2 *case such firefighter is unable to provide such in-*
3 *formation.*

4 (2) *REPORT TO CONGRESS.—The Secretary shall*
5 *submit the strategy described in paragraph (1) to the*
6 *Committee on Energy and Commerce of the House of*
7 *Representatives and the Committee on Health, Edu-*
8 *cation, Labor, and Pensions of the Senate not later*
9 *than 30 days after the date of the completion of the*
10 *strategy.*

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

21 (A) *How new information about firefighters*
22 *will be submitted to the Firefighter Registry for*
23 *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 as*
6 *the type of fire incident so attended in the case*
7 *such firefighter is unable to provide such infor-*
8 *mation.*

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

11 (e) *CONSULTATION AND REPORT.—The Secretary shall*
12 *consult with non-Federal experts on the Firefighter Registry*
13 *established under this section, and shall submit to the Com-*
14 *mittee on Health, Education, Labor, and Pensions of the*
15 *Senate and the Committee on Energy and Commerce of the*
16 *House of Representatives a report that includes, as appro-*
17 *priate, information on goals achieved and improvements*
18 *needed to strengthen the Firefighter Registry. Such non-*
19 *Federal experts shall include the following:*

20 (1) *Public health experts with experience in de-*
21 *veloping and maintaining cancer registries.*

22 (2) *Epidemiologists with experience in studying*
23 *cancer incidence.*

24 (3) *Clinicians with experience in diagnosing and*
25 *treating cancer incidence.*

1 (4) *Active and retired volunteer, paid-on-call,*
2 *and career firefighters as well as relevant national*
3 *fire and emergency response organizations.*

4 (f) *RESEARCH AVAILABILITY.—Subject to subsection*
5 *(g), the Secretary shall ensure that information and anal-*
6 *ysis in the Firefighter Registry are available, as appro-*
7 *priate, to the public, including researchers, firefighters, and*
8 *national fire service organizations.*

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

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

Attest:

Secretary.

115TH CONGRESS
2^D SESSION

H.R. 931

AMENDMENT