

114TH CONGRESS
2D SESSION

H. R. 4625

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 25, 2016

Mr. HANNA (for himself and Mr. PASCARELL) introduced the following bill;
which was referred to the Committee on Energy and Commerce

A BILL

To require the Secretary of Health and Human Services to develop a voluntary patient 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 2016”.

6 **SEC. 2. FINDINGS.**

7 Congress finds the following:

1 (1) Studies conducted since the 1990s have in-
2 dicated a strong link between firefighting and an in-
3 creased risk for several major cancers.

4 (2) The cancers identified as most common
5 among firefighters according to these studies include
6 testicular cancer, which male firefighters are 102
7 percent more likely to be diagnosed with, stomach
8 cancer, multiple myeloma, and brain cancer, among
9 several others.

10 (3) The heightened incidence of cancer among
11 firefighters has been attributed to their frequent ex-
12 posure to a range of harmful substances including
13 resultant pyrolysis products, toxic particulates, gases
14 and fumes, metals such as cadmium and lead, chem-
15 ical substances such as benzene and vinyl chloride,
16 and minerals such as asbestos and silicates.

17 (4) An extensive 2014 study conducted by the
18 National Institute of Occupational Safety and
19 Health (NIOSH) over the course of several years
20 and which included almost 30,000 firefighters found
21 that firefighters were at an increased risk of being
22 diagnosed with malignant mesothelioma and found
23 potential links between exposure to fire incidents
24 and heightened risks for lung cancer and leukemia,
25 among several others.

1 (5) Past studies examining cancer incidence
2 among firefighters have been limited by the avail-
3 ability and standardization of important epidemio-
4 logical data, relatively small sample sizes, inconsis-
5 tencies in the operationalization of key terms and
6 metrics, incomplete employment histories, and an
7 underrepresentation of minority, female, and volun-
8 teer firefighters.

9 (6) Today, many States across the country
10 maintain cancer registries that collect and collate in-
11 formation regarding cancer diagnoses, demographic
12 information, and treatment plans. State cancer reg-
13 istries have greatly contributed to overcoming these
14 obstacles by offering centralized repositories of infor-
15 mation, which researchers in the public and private
16 sectors can access when conducting research on can-
17 cer risks.

18 (7) While these State-based cancer registries
19 undoubtedly contribute to furthering research re-
20 lated to assessing cancer incidence among fire-
21 fighters, a special purpose national cancer registry
22 would provide researchers and public health agencies
23 with more direct and comprehensive access to the
24 specific set of information they need to conduct more

1 robust, focused, and epidemiologically rigorous re-
2 search on cancer incidence among firefighters.

3 (8) Efforts to understand cancer incidence
4 among firefighters through a specialized national
5 cancer registry will better inform the kinds of pre-
6 cautions firefighters should take in the future, im-
7 prove our understanding of key epidemiological
8 trends, and potentially lead to the development of
9 more sophisticated safety protocols to lower cancer
10 risks.

11 **SEC. 3. PATIENT REGISTRY FOR FIREFIGHTER CANCER IN-**
12 **CIDENCE.**

13 (a) IN GENERAL.—The Secretary of Health and
14 Human Services, acting through the Director of the Cen-
15 ters for Disease Control and Prevention, shall develop and
16 maintain a voluntary patient registry to collect data on
17 cancer incidence among firefighters.

18 (b) USE OF REGISTRY.—The patient registry shall be
19 used for the following purposes:

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

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

4 (c) RELEVANT DATA.—In carrying out the voluntary
5 data collection for purposes of inclusion under the patient
6 registry under subsection (a), the Secretary should seek
7 to include the following de-identified information:

8 (1) With respect to cancer diagnoses and treat-
9 ment of firefighters, de-identified information on—

10 (A) full detailing of physical examinations
11 and medical history;

12 (B) complete detailing of all relevant diag-
13 nostic tests and lab procedures;

14 (C) complete detailing of all pathology and
15 operative reports; and

16 (D) complete detailing of treatments un-
17 dergone or planned.

18 (2) With respect to individual patient history
19 relating to the incidence of cancer among fire-
20 fighters, de-identified information on—

21 (A) basic demographic information, includ-
22 ing the age of the firefighter involved and age
23 of onset of cancer;

1 (B) a listing of status of the firefighter as
2 either volunteer, paid-on-call, or career fire-
3 fighter;

4 (C) the number of years on the job and a
5 detailing of additional employment experience
6 that was either performed concurrently along-
7 side firefighting service or anytime thereafter;

8 (D)(i) a measure of the number of fire inci-
9 dents attended as well as the type of fire inci-
10 dents (such as residential house fire or commer-
11 cial fire); or

12 (ii) in the case of a firefighter who is un-
13 able to provide information on such number and
14 type, an estimate of such number and type
15 based on the method developed under sub-
16 section (d)(2); and

17 (E) a list of additional risk factors, includ-
18 ing smoking or drug use, as determined rel-
19 evant by the Secretary.

20 (3) Any additional information that is deemed
21 necessary by the Secretary.

22 (d) METHODS.—

23 (1) IN GENERAL.—For the purposes described
24 in subsection (b), the Secretary is authorized to in-
25 corporate questions into public health surveys, ques-

1 tionnaires, and other databases in existence as of the
2 date of enactment of this Act.

3 (2) 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 registry established
9 under this section.

10 (3) METHOD TO ESTIMATE NUMBER AND TYPE
11 OF FIRE INCIDENTS.—For purposes of subsection
12 (c)(2)(D), the Secretary, in consultation with the ex-
13 perts described in subsection (e), shall develop a reli-
14 able and standardized method for estimating the
15 number of fire incidents attended by a firefighter as
16 well as the type of fire incident so attended in the
17 case such firefighter is unable to provide such infor-
18 mation.

19 (e) CONSULTATION.—The Secretary shall, on a reg-
20 ular basis, seek feedback regarding the utility of the reg-
21 istry established under this section and ways the registry
22 can be improved from non-Federal experts in the following
23 areas:

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.—The Secretary shall
9 develop and make public an approval process for making
10 de-identified cancer registry data submitted for inclusion
11 in the patient registry developed under subsection (a)
12 available without a fee for public research purposes. Such
13 process shall provide that such data shall be made avail-
14 able for such research purposes only if there is an agree-
15 ment to make findings, journal articles, or other print or
16 web-based publications derived from such research public
17 or available to the relevant stakeholders identified in sub-
18 section (e)(4).

19 (g) PRIVACY.—In carrying out this Act, the Secretary
20 shall apply to the registry developed under subsection (a)
21 data security provisions and privacy standards that com-
22 ply with the best practices of the Centers for Disease Con-
23 trol and Prevention, as defined by the National Institute
24 of Standards and Technology in Special Publication 800–
25 37 revision 1, as well as the HIPAA privacy regulation,

1 as defined in section 1180(b)(3) of the Social Security Act
2 (42 U.S.C. 1320d-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 2017 through
6 2021.

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