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(Original Signature of Member)

114TH CONGRESS  
2D SESSION

**H. R.** \_\_\_\_\_

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

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**IN THE HOUSE OF REPRESENTATIVES**

Mr. HANNA (for himself and Mr. PASCRELL) introduced the following bill; which was referred to the Committee on \_\_\_\_\_

\_\_\_\_\_  
**A BILL**

To require the Secretary of Health and Human Service 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 1990's 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 under-representation 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 through 2017  
6 through 2021.