H. R. 931

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

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 7, 2017

Mr. Collins of New York (for himself, Mr. Pascrell, Mr. Amodei, Mr. Barletta, Mr. Barr, Mr. Blumenauer, Ms. Bonamici, Mr. Bost, Mrs. Brooks of Indiana, Ms. Brownley of California, Mrs. Bustos, Mrs. Comstock, Mr. Connolly, Mr. DeFazio, Ms. DeGette, Mr. Donovan, Mr. Ellison, Mr. Engel, Ms. Esty, Mr. Foster, Mr. Faso, Mr. Garamendi, Mr. Grijalva, Mr. Heck, Mr. Joyce of Ohio, Ms. Kaptur, Mr. Katko, Mr. Kilmer, Mr. Kind, Mr. King of New York, Mr. Knight, Ms. Kuster of New Hampshire, Mr. Levin, Mr. Lipinski, Mr. LoBiondo, Mr. Loebsack, Mrs. Carolyn B. Maloney of New York, Ms. McCollo, Mr. McGovern, Mr. Meehan, Mr. Moulton, Mr. Nadler, Mr. Nolan, Mr. Norcross, Ms. Norton, Mr. Payne, Mr. Perlmutter, Mr. Peterson, Ms. Pingree, Mr. Poliquin, Mr. Renacci, Miss Rice of New York, Mr. Rogers of Kentucky, Mr. Ryan of Ohio, Mr. Serrano, Ms. Shea-Porter, Mr. Shuster, Ms. Sinema, Mr. Sires, Ms. Slaughter, Mr. Smith of New Jersey, Mr. Swalwell of California, Ms. Tenney, Mr. Tonko, Ms. Tsongas, Mr. Valadao, Mrs. Walorski, Mr. Walz, Ms. Wasserman Schultz, Mrs. Watson Coleman, Mr. Yarmuth, Mr. Young of Alaska, Mr. Zeldin, Mr. Lance, Mr. Smith of Washington, Mr. Sean Patrick Maloney of New York, Mr. Quigley, Mr. Gottheimer, and Ms. Stefanik) 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 registry to collect data on cancer incidence among firefighters.
Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

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

SEC. 2. PATIENT REGISTRY FOR FIREFIGHTER CANCER INCIDENCE.

(a) IN GENERAL.—The Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention, shall develop and maintain, directly or through a grant or cooperative agreement, a voluntary registry of firefighters (referred to in this section as the “Firefighter Registry”) to collect relevant history and occupational information of such firefighters that can be linked to available cancer registry data collected by existing State cancer registries.

(b) USE OF FIREFIGHTER REGISTRY.—The Firefighter Registry shall be used for the following purposes:

(1) To establish and improve collection infrastructure and activities related to the nationwide monitoring of the incidence of cancer among firefighters.

(2) To collect, consolidate, store, and make publicly available epidemiological information related to cancer incidence and trends among firefighters.
(c) RELEVANT DATA.—

(1) IN GENERAL.—In carrying out the voluntary data collection for purposes of inclusion under the Firefighter Registry, the Secretary should seek to include the following information:

(A) Identifiable information from a representative sample size, as determined by the Secretary under subsection (d)(2)(A), of volunteer, paid-on-call, and career firefighters, independent of cancer status or diagnosis.

(B) With respect to individual risk factors and work history of firefighters, available information on—

(i) basic demographic information, including the age of the firefighter involved;

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

(iii) the number of years on the job and a detailing of additional employment experience that was either performed concurrently alongside firefighting service, before, or anytime thereafter;

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

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

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

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

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

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

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

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

(d) METHODS.—

(1) IN GENERAL.—For the purposes described in subsection (b), the Secretary is authorized to incorporate questions into public health surveys, questionnaires, and other databases.

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

(A) Identified minimum participation targets for volunteer, paid-on-call, and career firefighters.

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

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

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

(E) Working in consultation with the ex-
perts described in subsection (e), a reliable and
standardized method for estimating the number
of fire incidents attended by a firefighter as
well as the type of fire incident so attended in
the case such firefighter is unable to provide
such information.

(3) REPORT TO CONGRESS.—The Secretary
shall submit the strategy described in paragraph (2)
to the Committee on Energy and Commerce of the
House of Representatives and the Committee on
Health, Education, Labor, and Pensions of the Sen-
ate not later than 30 days after the date of the com-
pletion of the strategy.
(4) **GUIDANCE FOR INCLUSION AND MAINTENANCE OF DATA ON FIREFIGHTERS.**—The Secretary shall develop, in consultation with the stakeholders identified in subsection (e), and disseminate guidance to State health agencies, State departments of homeland security, and volunteer, paid-on-call, combination, and career firefighting agencies that outlines the following:

(A) How new information about firefighters will be submitted to the Firefighter Registry for inclusion.

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

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

(D) Further information, as deemed necessary by the Secretary.

(5) **ENSURING REPRESENTATION OF UNDERREPRESENTED GROUPS IN REGISTRY.**—In carrying out this section, the Secretary shall take such measures as the Secretary deems appropriate to encour-
age the inclusion of data on minority, female, and
volunteer firefighters in the Firefighter Registry es-
tablished under this section.

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

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

(2) Epidemiologists with experience in studying
cancer incidence.

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

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

(f) RESEARCH AVAILABILITY.—The Secretary shall
develop and make public a process for de-identifying data
from the Firefighter Registry and making such data avail-
able without a fee for research or other purposes. Such
process shall provide that such data shall be made avail-
able for such research purposes only if there is an agree-
ment to make findings, journal articles, or other print or
web-based publications derived from such research public
or available to the relevant stakeholders identified in subsection (e).

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

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