

One Hundred Fifteenth Congress
of the
United States of America

AT THE SECOND SESSION

*Begun and held at the City of Washington on Wednesday,
the third day of January, two thousand and eighteen*

An Act

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 2018.

SEC. 2. VOLUNTARY REGISTRY FOR FIREFIGHTER CANCER INCIDENCE.

(a) **IN GENERAL.**—The Secretary of Health and Human Services (referred to in this section as the Secretary), acting through the Director of the Centers for Disease Control and Prevention and in coordination with other agencies as the Secretary determines appropriate, 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 health and occupational information of such firefighters for purposes of determining cancer incidence.

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

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

(2) To collect, consolidate, and maintain, consistent with subsection (g), epidemiological information and analyses related to cancer incidence and trends among firefighters

(c) **RELEVANT DATA.**—

(1) **DATA COLLECTION.**—In carrying out the voluntary data collection for purposes of inclusion under the Firefighter Registry, the Secretary may collect the following:

(A) Information, as determined by the Secretary under subsection (d)(1), of volunteer, paid-on-call, and career firefighters, independent of cancer status or diagnosis.

(B) Individual risk factors and occupational history of firefighters.

(C) Information, if available, related to—

(i) basic demographic information, including—

(I) the age of the firefighter involved during the relevant dates of occupation as a firefighter; and

(II) the age of cancer diagnosis;

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

(iii) the total number of years of occupation as a firefighter and a detailing of additional employment experience, whether concurrent, before, or anytime thereafter;

(iv)(I) the approximate number of fire incidents attended, including information related to the type of fire incidents and the role of the firefighter in responding to the incident; or

(II) in the case of a firefighter for whom information on such number and type is unavailable, an estimate of such number and type based on the method developed under subsection (d)(1)(D); and

(v) other medical information and health history, including additional risk factors, as appropriate, and other information relevant to a cancer incidence study of firefighters.

(2) INFORMATION ON DIAGNOSES AND TREATMENT.—In carrying out paragraph (1), with respect to diagnoses and treatment of firefighters with cancer, the Secretary shall, as appropriate, enable the Firefighter Registry to electronically connect 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—

(A) 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) FIREFIGHTER REGISTRY COORDINATION STRATEGY.—

(1) REQUIRED STRATEGY.—The Secretary shall, in consultation with the relevant stakeholders identified in subsection (e), including epidemiologists and pathologists, develop a strategy to coordinate data collection activities, including within existing State registries, for inclusion in the Firefighter Registry established under this Act. The strategy may include the following:

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

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

(C) Information on how the Secretary will store data described in subsection (c)(1) and provide electronic access to relevant health information described in subsection (c)(2).

(D) Working in consultation with the experts 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.

(2) REPORT TO CONGRESS.—The Secretary shall submit the strategy described in paragraph (1) to the Committee on Energy

and Commerce of the House of Representatives and the Committee on Health, Education, Labor, and Pensions of the Senate not later than 30 days after the date of the completion of the strategy.

(3) GUIDANCE FOR INCLUSION AND MAINTENANCE OF DATA ON FIREFIGHTERS.—The Secretary shall develop, in consultation with the stakeholders identified in subsection (e), State health agencies, State departments of homeland security, and volunteer, paid-on-call, combination, and career firefighting agencies, a strategy for inclusion of firefighters in the registry that are representative of the general population of firefighters, 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.

(e) CONSULTATION AND REPORT.—The Secretary shall consult with non-Federal experts on the Firefighter Registry established under this section, and shall submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives a report that includes, as appropriate, information on goals achieved and improvements needed to strengthen the Firefighter Registry. Such non-Federal experts shall include the following:

(1) Public health experts with experience in developing 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.—Subject to subsection (g), the Secretary shall ensure that information and analysis in the Firefighter Registry are available, as appropriate, to the public, including researchers, firefighters, and national fire service organizations.

(g) PRIVACY.—In carrying out this Act, the Secretary shall ensure that information in and analysis of the Firefighter Registry are made available in a manner that, at a minimum, protects personal privacy to the extent required by applicable Federal and State privacy law.

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(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.

Speaker of the House of Representatives.

*Vice President of the United States and
President of the Senate.*