

search strides made, most of those children die. Up to 75 percent of the children with cancer can now be cured.

“(7) The causes of most childhood cancers are not yet known.

“(8) Childhood cancers are mostly those of the white blood cells (leukemias), brain, bone, the lymphatic system, and tumors of the muscles, kidneys, and nervous system. Each of these behaves differently, but all are characterized by an uncontrolled proliferation of abnormal cells.

“(9) Eighty percent of the children who are diagnosed with cancer have disease which has already spread to distant sites in the body.

“(10) Ninety percent of children with a form of pediatric cancer are treated at one of the more than 200 Children’s Oncology Group member institutions throughout the United States.

“SEC. 3. PURPOSES

“It is the purpose of this Act [see Short Title of 2008 Amendment note set out under section 201 of this title] to authorize appropriations to—

“(1) encourage the support for pediatric cancer research and other activities related to pediatric cancer;

“(2) establish a comprehensive national childhood cancer registry; and

“(3) provide informational services to patients and families affected by childhood cancer.”

§ 280e-4. Authorization of appropriations

(a) Registries

For the purpose of carrying out this part (other than section 280e-3a of this title), there are authorized to be appropriated \$30,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 2003. Of the amounts appropriated under the preceding sentence for any such fiscal year, the Secretary may obligate not more than 25 percent for carrying out section 280e-1 of this title, and not more than 10 percent may be expended for assessing the accuracy, completeness and quality of data collected, and not more than 10 percent of which is to be expended under section 280e-2 of this title.

(b) Breast cancer study

Of the amounts appropriated for the National Cancer Institute under subpart 1 of part C of subchapter III for any fiscal year in which the study required in section 280e-3 of this title is being carried out, the Secretary shall expend not less than \$1,000,000 for the study.

(July 1, 1944, ch. 373, title III, § 399F, formerly § 399L, as added Pub. L. 102-515, § 3, Oct. 24, 1992, 106 Stat. 3376; amended Pub. L. 103-43, title XX, § 2003, June 10, 1993, 107 Stat. 208; Pub. L. 103-183, title VII, § 705(c), Dec. 14, 1993, 107 Stat. 2241; Pub. L. 105-340, title II, § 202, Oct. 31, 1998, 112 Stat. 3194; renumbered § 399F and amended Pub. L. 106-310, div. A, title V, § 502(2)(A), (D), Oct. 17, 2000, 114 Stat. 1115; Pub. L. 110-285, § 4(b)(2), July 29, 2008, 122 Stat. 2631.)

Editorial Notes

PRIOR PROVISIONS

A prior section 399F of act July 1, 1944, was renumbered section 399G and is classified to section 280e-11 of this title.

AMENDMENTS

2008—Subsec. (a). Pub. L. 110-285 inserted “(other than section 280e-3a of this title)” after “this part”.

2000—Subsec. (a). Pub. L. 106-310, § 502(2)(D)(ii), substituted “section 280e-2 of this title” for “subsection 280e-2 of this title”.

Pub. L. 106-310, § 502(2)(D)(i), made technical amendment to reference in original act which appears in text as reference to section 280e-1 of this title.

Subsec. (b). Pub. L. 106-310, § 502(2)(D)(iii), made technical amendment to reference in original act which appears in text as reference to section 280e-3 of this title.

1998—Subsec. (a). Pub. L. 105-340 substituted “2003” for “1998”.

1993—Subsec. (a). Pub. L. 103-183 substituted “through 1998” for “through 1996”.

Pub. L. 103-43 substituted “there are authorized to be appropriated \$30,000,000 for fiscal year 1994, and such sums as may be necessary for each of the fiscal years 1995 through 1996” for “the Secretary may use \$30,000,000 for each of the fiscal years 1993 through 1997” in first sentence and “Of the amounts appropriated under the preceding sentence” for “Out of any amounts used” in second sentence.

§ 280e-5. 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 firefighters¹

(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;

¹ So in original. Probably should be followed by a period.

(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 280e(c)(2)(D) of this title, 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 Rep-

resentatives 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.

(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.

(Pub. L. 115-194, §2, July 7, 2018, 132 Stat. 1506.)

Editorial Notes

REFERENCES IN TEXT

This Act, referred to in subsecs. (d)(1) and (g), is Pub. L. 115-194, July 7, 2018, 132 Stat. 1506, known as the Firefighter Cancer Registry Act of 2018, which enacted this section and provisions set out as a note under section 201 of this title. For complete classification of this Act to the Code, see Short Title of 2018 Amendment note set out under section 201 of this title and Tables.

CODIFICATION

Section was enacted as part of the Firefighter Cancer Registry Act of 2018, and not as part of the Public Health Service Act which comprises this chapter.

PART N—NATIONAL FOUNDATION FOR THE CENTERS FOR DISEASE CONTROL AND PREVENTION

Editorial Notes

CODIFICATION

This part was formerly set out preceding part M of this subchapter.

§ 280e-11. Establishment and duties of Foundation**(a) In general**

There shall be established in accordance with this section a nonprofit private corporation to be known as the National Foundation for the Centers for Disease Control and Prevention (in this part referred to as the “Foundation”). The Foundation shall not be an agency or instrumentality of the Federal Government, and officers, employees, and members of the board of the Foundation shall not be officers or employees of the Federal Government.

(b) Purpose of Foundation

The purpose of the Foundation shall be to support and carry out activities for the prevention and control of diseases, disorders, injuries, and disabilities, and for promotion of public health.

(c) Endowment fund**(1) In general**

In carrying out subsection (b), the Foundation shall establish a fund for providing endowments for positions that are associated with the Centers for Disease Control and Prevention and dedicated to the purpose described in such subsection. Subject to subsection (f)(1)(B), the fund shall consist of such donations as may be provided by non-Federal entities and such non-Federal assets of the Foundation (including earnings of the Foundation and the fund) as the Foundation may elect to transfer to the fund.

(2) Authorized expenditures of fund

The provision of endowments under paragraph (1) shall be the exclusive function of the fund established under such paragraph. Such endowments may be expended only for the compensation of individuals holding the positions, for staff, equipment, quarters, travel, and other expenditures that are appropriate in supporting the positions, and for recruiting individuals to hold the positions endowed by the fund.

(d) Certain activities of Foundation

In carrying out subsection (b), the Foundation may provide for the following with respect to the purpose described in such subsection:

(1) Programs of fellowships for State and local public health officials to work and study in association with the Centers for Disease Control and Prevention.

(2) Programs of international arrangements to provide opportunities for public health officials of other countries to serve in public health capacities in the United States in association with the Centers for Disease Control and Prevention or elsewhere, or opportunities for employees of such Centers (or other public health officials in the United States) to serve in such capacities in other countries, or both.

(3) Studies, projects, and research (which may include applied research on the effectiveness of prevention activities, demonstration projects, and programs and projects involving international, Federal, State, and local governments).

(4) Forums for government officials and appropriate private entities to exchange information. Participants in such forums may include institutions of higher education and appropriate international organizations.

(5) Meetings, conferences, courses, and training workshops.

(6) Programs to improve the collection and analysis of data on the health status of various populations.

(7) Programs for writing, editing, printing, and publishing of books and other materials.

(8) Other activities to carry out the purpose described in subsection (b).

(e) General structure of Foundation; nonprofit status**(1) Board of directors**

The Foundation shall have a board of directors (in this part referred to as the “Board”), which shall be established and conducted in accordance with subsection (f). The Board shall establish the general policies of the Foundation for carrying out subsection (b), including the establishment of the bylaws of the Foundation.

(2) Executive director

The Foundation shall have an executive director (in this part referred to as the “Director”), who shall be appointed by the Board, who shall serve at the pleasure of the Board, and for whom the Board shall establish the rate of compensation. Subject to compliance with the policies and bylaws established by the Board pursuant to paragraph (1), the Director shall be responsible for the daily operations of the Foundation in carrying out subsection (b).

(3) Nonprofit status

In carrying out subsection (b), the Board shall establish such policies and bylaws under paragraph (1), and the Director shall carry out such activities under paragraph (2), as may be necessary to ensure that the Foundation maintains status as an organization that—

(A) is described in subsection (c)(3) of section 501 of title 26; and

(B) is, under subsection (a) of such section, exempt from taxation.