subsequent fiscal years, see section 109 of Pub. L. 109–482, set out as a note under section 281 of this title.

§ 285a–10. Research, information, and education with respect to blood cancer

(a) Joe Moakley Research Excellence Program

(1) In general

The Director of NIH shall expand, intensify, and coordinate programs for the conduct and support of research with respect to blood cancer, and particularly with respect to leukemia, lymphoma, and multiple myeloma.

(2) Administration

The Director of NIH shall carry out this subsection through the Director of the National Cancer Institute and in collaboration with any other agencies that the Director determines to be appropriate.

(b) Geraldine Ferraro Cancer Education Program

(1) In general

The Secretary shall direct the appropriate agency within the Department of Health and Human Services, in collaboration with the Director of NIH, to establish and carry out a program to provide information and education for patients and the general public with respect to blood cancer, and particularly with respect to the treatment of leukemia, lymphoma, and multiple myeloma.

(2) Administration

The Agency determined by the Secretary under paragraph (1) shall carry out this subsection in collaboration with private health organizations that have national education and patient assistance programs on blood-related cancers.

(July 1, 1944, ch. 373, title IV, § 417D, as added Pub. L. 107–172, § 3, May 14, 2002, 116 Stat. 541; amended Pub. L. 109–482, title I, § 103(b)(17), Jan. 15, 2007, 120 Stat. 3688; Pub. L. 115–180, title II, § 204(a), June 5, 2018, 132 Stat. 1390.)

Editorial Notes

AMENDMENTS

2018—Pub. L. 115–180 made technical correction to directory language of Pub. L. 107–172, § 3, which enacted this section.

2007—Subsec. (a)(3). Pub. L. 109–482, § 103(b)(17)(A), struck out heading and text of par. (3). Text read as follows: ''For the purpose of carrying out this subsection, there is authorized to be appropriated such sums as may be necessary for fiscal year 2002 and each subsequent fiscal year. Such authorizations of appropriations are in addition to other authorizations of appropriations that are available for such purpose.''

Subsec. (b)(3). Pub. L. 109–482, § 103(b)(17)(B), struck out heading and text of par. (3). Text read as follows: ''For the purpose of carrying out this subsection, there is authorized to be appropriated such sums as may be necessary for fiscal year 2002 and each subsequent fiscal year. Such authorizations of appropriations are in addition to other authorizations of appropriations that are available for such purpose.''

Statutory Notes and Related Subsidiaries

EFFECTIVE DATE OF 2018 AMENDMENT

Pub. L. 115–180, title II, § 204(b), June 5, 2018, 132 Stat. 1390, provided that: ''The amendment made by subsection (a) [amending section 3 of Pub. L. 107–172] shall take effect as if included in section 3 of the Hematological Cancer Research Investment and Education Act of 2002 (Public Law 107–172; 116 Stat. 541) [enacting this section].''

EFFECTIVE DATE OF 2007 AMENDMENT

Amendment by Pub. L. 109–482 applicable only with respect to amounts appropriated for fiscal year 2007 or subsequent fiscal years, see section 109 of Pub. L. 109–482, set out as a note under section 281 of this title.

CONGRESSIONAL FINDINGS

Pub. L. 107–172, § 2, May 14, 2002, 116 Stat. 541, provided that: ''Congress finds that:

''(1) An estimated 109,500 people in the United States will be diagnosed with leukemia, lymphoma, and multiple myeloma in 2001.

''(2) New cases of the blood cancers described in paragraph (1) account for 8.6 percent of new cancer cases.

''(3) Those devastating blood cancers will cause the deaths of an estimated 60,300 persons in the United States in 2001. Every 9 minutes, a person in the United States dies from leukemia, lymphoma, or multiple myeloma.

''(4) While less than 5 percent of Federal funds for cancer research are spent on those blood cancers, those blood cancers cause 11 percent of all cancer deaths in the United States.

''(5) Increased Federal support of research into leukemia, lymphoma, and multiple myeloma has resulted and will continue to result in significant advances in the treatment, and ultimately the cure, of those blood cancers as well as other cancers.''

§ 285a–11. Pediatric cancer research, awareness, and survivorship

(a) Children's cancer biorepositories

(1) Award

The Secretary, acting through the Director of NIH, may make awards to an entity or entities described in paragraph (4) to build upon existing research efforts to collect biospecimens and clinical and demographic information of children, adolescents, and young adults with selected cancer subtypes (and their recurrences) for which current treatments are least effective, in order to achieve a better understanding of the causes of such cancer subtypes (and their recurrences), and the effects and outcomes of treatments for such cancers.

(2) Use of funds

Amounts received under an award under paragraph (1) may be used to carry out the following:

(A) Collect and store high-quality, donated biospecimens and associated clinical and demographic information on children, adolescents, and young adults diagnosed with cancer in the United States, focusing on children, adolescents, and young adults with cancer enrolled in clinical trials for whom current treatments are least effective. Activities under this subparagraph may include storage of biospecimens and associated clinical and demographic data at existing biorepositories supported by the National Cancer Institute, such as collected samples of both solid tumor cancer and paired samples.

(B) Maintain an interoperable, secure, and searchable database on stored biospecimens

and associated clinical and demographic data from children, adolescents, and young adults with cancer for the purposes of research by scientists and qualified health care professionals.

(C) Establish and implement procedures for evaluating applications for access to such biospecimens and clinical and demographic data from researchers and other qualified health care professionals.

(D) Provide access to biospecimens and clinical and demographic data from children, adolescents, and young adults with cancer to researchers and qualified health care professionals for peer-reviewed research—

(i) consistent with the procedures established pursuant to subparagraph (C);

(ii) only to the extent permitted by applicable Federal and State law; and

(iii) in a manner that protects personal privacy to the extent required by applicable Federal and State privacy law, at minimum.

(3) No requirement

No child, adolescent, or young adult with cancer shall be required under this subsection to contribute a specimen to a biorepository or share clinical or demographic data.

(4) Application; considerations

(A) Application

To be eligible to receive an award under paragraph (1) an entity shall submit an application to the Secretary at such a time, in such manner, and containing such information as the Secretary may reasonably require.

(B) Considerations

In evaluating applications submitted under subparagraph (A), the Secretary shall consider the existing infrastructure of the entity that would allow for the timely capture of biospecimens and related clinical and demographic information for children, adolescents, and young adults with cancer for whom current treatments are least effective.

(5) Privacy protections and informed consent

(A) In general

The Secretary may not make an award under paragraph (1) to an entity unless the Secretary ensures that such entity—

(i) collects biospecimens and associated clinical and demographic information only from participants who have given their informed consent in accordance with Federal and State law; and

(ii) protects personal privacy to the extent required by applicable Federal and State law, at minimum.

(B) Informed consent

The Secretary shall ensure biospecimens and associated clinical and demographic information are collected with informed consent, as described in subparagraph (A)(i).

(6) Guidelines and oversight

The Secretary shall develop and disseminate appropriate guidelines for the development and maintenance of the biorepositories supported under this subsection, including appropriate oversight, to facilitate further research on select cancer subtypes (and their recurrences) in children, adolescents, and young adults with such cancers (and their recurrences).

(7) Coordination

To encourage the greatest possible efficiency and effectiveness of federally supported efforts with respect to the activities described in this subsection, the Secretary shall ensure the appropriate coordination of programs supported under this section with existing federally supported cancer registry programs and the activities under section 280e–3a of this title, as appropriate.

(8) Supplement not supplant

Funds provided under this subsection shall be used to supplement, and not supplant, Federal and non-Federal funds available for carrying out the activities described in this subsection.

(9) Report

Not later than 4 years after January 5, 2023, the Secretary shall submit to Congress a report on—

(A) the number of biospecimens and corresponding clinical demographic data collected through the biospecimen research efforts supported under paragraph (1);

(B) the number of biospecimens and corresponding clinical demographic data requested for use by researchers;

(C) barriers to the collection of biospecimens and corresponding clinical demographic data;

(D) barriers experienced by researchers or health care professionals in accessing the biospecimens and corresponding clinical demographic data necessary for use in research; and

(E) recommendations with respect to improving the biospecimen and biorepository research efforts under this subsection.

(10) Report on researcher access to children's cancer biorepository samples

Not later than 2 years after January 5, 2023, the Director of NIH shall—

(A) conduct a review of the procedures established under paragraph (2)(C) and other policies or procedures related to researcher access to such biospecimens to identify any opportunities to reduce administrative burden, consistent with paragraph (2)(D), in a manner that protects personal privacy to the extent required by applicable Federal and State privacy law, at a minimum; and

(B) 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 on the findings of the review under subparagraph (A) and whether the Director of NIH plans to make any changes to the policies or procedures considered in such review, based on such findings.

(11) Definitions

For purposes of this subsection:

(A) Award

The term ''award'' includes a grant, contract, or cooperative agreement determined by the Secretary.

(B) Biospecimen

The term ''biospecimen'' includes—

(i) solid tumor tissue or bone marrow;

(ii) normal or control tissue;

(iii) blood and plasma;

(iv) DNA and RNA extractions;

(v) familial DNA; and

(vi) any other sample relevant to cancer research, as required by the Secretary.

(C) Clinical and demographic information

The term ''clinical and demographic information'' includes—

(i) date of diagnosis;

(ii) age at diagnosis;

(iii) the patient's sex, race, ethnicity, and environmental exposures;

(iv) extent of disease at enrollment;

(v) site of metastases;

(vi) location of primary tumor coded;

(vii) histologic diagnosis;

(viii) tumor marker data when available;

(ix) treatment and outcome data;

(x) information related to specimen quality; and

(xi) any other applicable information required by the Secretary.

(b) Improving care for pediatric cancer survivors

(1) Research on pediatric cancer survivorship

The Director of NIH, in coordination with ongoing research activities, may continue to conduct or support pediatric cancer survivorship research including in any of the following areas:

(A) Outcomes of pediatric cancer survivors, including within minority or other medically underserved populations and with respect to health disparities of such outcomes.

(B) Barriers to follow-up care for pediatric cancer survivors, including within minority or other medically underserved populations.

(C) The impact of relevant factors, which may include familial, socioeconomic, and other environmental factors, on treatment outcomes and survivorship.

(D) The development of indicators used for long-term follow-up and analysis of the late effects of cancer treatment for pediatric cancer survivors.

(E) The identification of, as applicable—

(i) risk factors associated with the late effects of cancer treatment;

(ii) predictors of adverse neurocognitive and psychosocial outcomes; and

(iii) the molecular basis of long-term complications.

(F) The development of targeted interventions to reduce the burden of morbidity borne by cancer survivors in order to protect such cancer survivors from the late effects of cancer.

(2) Balanced approach

In conducting or supporting research under paragraph (1)(A)(i) on pediatric cancer survivors within minority or other medically underserved populations, the Director of NIH shall ensure that such research addresses both the physical and the psychological needs of such survivors, as appropriate.

(c) Rule of construction

Nothing in this section shall be construed as being inconsistent with the goals and purposes of the Minority Health and Health Disparities Research and Education Act of 2000.

(d) Authorization of appropriations

For purposes of carrying out this section and section 280e–3a of this title, there are authorized to be appropriated $30,000,000 for each of fiscal years 2024 through 2028. Funds appropriated under this subsection shall remain available until expended.

(July 1, 1944, ch. 373, title IV, § 417E, as added Pub. L. 110–285, § 4(a), July 29, 2008, 122 Stat. 2629; amended Pub. L. 115–180, title I, §§ 101, 102(b), title II, § 202, June 5, 2018, 132 Stat. 1383, 1386, 1389; Pub. L. 117–350, § 2(a), Jan. 5, 2023, 136 Stat. 6262.)

Editorial Notes

REFERENCES IN TEXT

The Minority Health and Health Disparities Research and Education Act of 2000, referred to in subsec. (c), is Pub. L. 106–525, Nov. 22, 2000, 114 Stat. 2495. For complete classification of this Act to the Code, see Short Title of 2000 Amendments note set out under section 201 of this title and Tables.

AMENDMENTS

2023—Subsec. (a)(2)(A). Pub. L. 117–350, § 2(a)(1)(A), inserted '', such as collected samples of both solid tumor cancer and paired samples'' after ''National Cancer Institute''.

Subsec. (a)(9). Pub. L. 117–350, § 2(a)(1)(B), substituted ''January 5, 2023'' for ''June 5, 2018'' in introductory provisions.

Subsec. (a)(10), (11). Pub. L. 117–350, § 2(a)(1)(C), (D), added par. (10) and redesignated former par. (10) as (11).

Subsec. (d). Pub. L. 117–350, § 2(a)(2), substituted ''2024 through 2028'' for ''2019 through 2023''.

2018—Pub. L. 115–180, § 101(1), substituted ''research, awareness, and survivorship'' for ''research and awareness'' in section catchline.

Subsec. (a). Pub. L. 115–180, § 101(2), added subsec. (a) and struck out former subsec. (a). Prior to amendment, text read as follows:

''(1) PROGRAMS OF RESEARCH EXCELLENCE IN PEDIATRIC CANCER.—The Secretary, in collaboration with the Director of NIH and other Federal agencies with interest in prevention and treatment of pediatric cancer, shall continue to enhance, expand, and intensify pediatric cancer research and other activities related to pediatric cancer, including therapeutically applicable research to generate effective treatments, pediatric preclinical testing, and pediatric clinical trials through National Cancer Institute-supported pediatric cancer clinical trial groups and their member institutions. In enhancing, expanding, and intensifying such research and other activities, the Secretary is encouraged to take into consideration the application of such research and other activities for minority, health disparity, and medically underserved communities. For purposes of this section, the term 'pediatric cancer research' means research on the causes, prevention, diagnosis, recognition, treatment, and long-term effects of pediatric cancer.

''(2) PEER REVIEW REQUIREMENTS.—All grants awarded under this subsection shall be awarded in accordance with section 289a of this title.''

Subsec. (b). Pub. L. 115–180, § 202, added subsec. (b) and struck out former subsec. (b) which related to public awareness of pediatric cancers and available treatments and research.

Subsec. (c). Pub. L. 115–180, § 101(3), struck out ''(42 U.S.C. 202 note)'' before period at end.

Subsec. (d). Pub. L. 115–180, § 102(b), substituted ''2019 through 2023'' for ''2009 through 2013'' and struck out ''Such authorization of appropriations is in addition to the authorization of appropriations established in section 282a of this title with respect to such purpose.'' before ''Funds appropriated''.

Statutory Notes and Related Subsidiaries

REPORTING ON CHILDHOOD CANCER RESEARCH PROJECTS

Pub. L. 115–180, title I, § 121, June 5, 2018, 132 Stat. 1387, provided that: ''The Director of the National Institutes of Health shall ensure that childhood cancer research projects conducted or supported by the National Institutes of Health are included in appropriate reports to Congress, which may include the Pediatric Research Initiative report.''

§ 285a–11a. Cancer survivorship programs

(a) Research to evaluate model systems of care for pediatric cancer survivors

(1) In general

The Secretary of Health and Human Services (referred to in this section as the ''Secretary'') shall, as appropriate, make awards to eligible entities to conduct or support research to develop, study, or evaluate approaches for monitoring and caring for childhood and adolescent cancer survivors throughout their lifespan, including transition to adult care and care coordination.

(2) Awards

(A) Types of entities

In making awards under this subsection, the Secretary shall, to the extent practicable, within the existing peer review process, include—

(i) small, medium, and large-sized eligible entities; and

(ii) sites located in different geographic areas, including rural and urban areas.

(B) Eligible entities

In this subsection, the term ''eligible entity'' means—

(i) a medical school;

(ii) a children's hospital;

(iii) a cancer center;

(iv) a community-based medical facility; or

(v) any other entity with significant experience and expertise in carrying out the activities described in paragraph (1).

(3) Use of funds

Funds awarded under this subsection may be used—

(A) to develop, study, or evaluate one or more models for monitoring and caring for cancer survivors; and

(B) in developing, studying, and evaluating such models, to give special emphasis to—

(i) design of models of follow-up care, monitoring, and other survivorship programs (including peer support and mentoring programs);

(ii) development of models for providing multidisciplinary care;

(iii) dissemination of information to health care providers about culturally and linguistically appropriate follow-up care for cancer survivors and their families, as appropriate and practicable;

(iv) development of psychosocial and support programs to improve the quality of life of cancer survivors and their families, which may include peer support and mentoring programs;

(v) design tools to support the secure electronic transfer of treatment information and care summaries between health care providers or, as applicable and appropriate, longitudinal childhood cancer survivorship cohorts (including risk factors and a plan for recommended follow-up care);

(vi) dissemination of the information and programs described in clauses (i) through (v) to other health care providers (including primary care physicians and internists) and to cancer survivors and their families, where appropriate and in accordance with Federal and State law; and

(vii) development of initiatives that promote the coordination and effective transition of care between cancer care providers, primary care physicians, mental health professionals, and other health care professionals, as appropriate, including models that use a team-based or multi-disciplinary approach to care.

(b) Workforce development for health care providers on medical and psychosocial care for childhood cancer survivors

(1) In general

The Secretary shall, not later than 1 year after January 5, 2023, conduct a review of the activities of the Department of Health and Human Services related to workforce development for health care providers who treat pediatric cancer patients and survivors. Such review shall include—

(A) identification of existing models relevant to providing medical and psychosocial services to individuals surviving pediatric cancers, and programs related to training for health professionals who provide such services to individuals surviving pediatric cancers; and

(B) recommendations for enhancing or promoting activities of the Department of Health and Human Services related to workforce development for health care providers who provide psychosocial care to pediatric cancer patients and survivors.

(2) Report

Not later than 2 years after January 5, 2023, the Secretary shall submit to the Committee on Health, Education, Labor, and Pensions of the Senate and Committee on Energy and Commerce of the House of Representatives, a report concerning the findings and recommendations from the review conducted under paragraph (1).

(Pub. L. 115–180, title II, § 201, June 5, 2018, 132 Stat. 1387; Pub. L. 117–350, § 2(b), Jan. 5, 2023, 136 Stat. 6263.)