(5) the diagnostic confirmation of positive screening results;

(6) ensuring the availability of treatment and management resources;

(7) educating families about newborn screening; and

(8) carrying out other activities determined appropriate by the Secretary.

(July 1, 1944, ch. 373, title XI, § 1115, as added Pub. L. 110–204, § 7, Apr. 24, 2008, 122 Stat. 711; amended Pub. L. 113–240, § 8, Dec. 18, 2014, 128 Stat. 2855.)

AMENDMENTS

2014—Subsec. (a). Pub. L. 113–240 substituted ''consortium'' for ''consortia'' and inserted at end ''The plan shall be updated as needed and at least every five years.''

§ 300b–15. Hunter Kelly Research Program

(a) Newborn screening activities

(1) In general

The Secretary, in conjunction with the Director of the National Institutes of Health and taking into consideration the recommendations of the Advisory Committee, may continue carrying out, coordinating, and expanding research in newborn screening (to be known as ''Hunter Kelly Newborn Screening Research Program'') including—

(A) identifying, developing, and testing the most promising new screening technologies, in order to improve already existing screening tests, increase the specificity of newborn screening, and expand the number of conditions for which screening tests are available;

(B) experimental treatments and disease management strategies for additional newborn conditions, and other genetic, metabolic, hormonal, or functional conditions that can be detected through newborn screening for which treatment is not yet available;

(C) providing research findings and data for newborn conditions under review by the Advisory Committee on Heritable Disorders in Newborns and Children to be added to the recommended uniform screening panel;

(D) conducting pilot studies on conditions recommended by the Advisory Committee on Heritable Disorders in Newborns and Children to ensure that screenings are ready for nationwide implementation; and

(E) other activities that would improve newborn screening, as identified by the Director.

(2) Additional newborn condition

For purposes of this subsection, the term ''additional newborn condition'' means any condition that is not one of the core conditions recommended by the Advisory Committee and adopted by the Secretary.

(b) Funding

In carrying out the research program under this section, the Secretary and the Director shall ensure that entities receiving funding through the program will provide assurances, as practicable, that such entities will work in consultation with the appropriate State departments of health, and, as practicable, focus their research on screening technology not currently performed in the States in which the entities are located, and the conditions on the uniform screening panel (or the standard test existing on the uniform screening panel).

(c) Reports

The Director is encouraged to include information about the activities carried out under this section in the biennial report required under section 283 of this title. If such information is included, the Director shall make such information available to be included on the Internet Clearinghouse established under section 300b–11 of this title.

(d) Nonduplication

In carrying out programs under this section, the Secretary shall minimize duplication and supplement, not supplant, existing efforts of the type carried out under this section.

(e) Peer review

Nothing in this section shall be construed to interfere with the scientific peer-review process at the National Institutes of Health.

(July 1, 1944, ch. 373, title XI, § 1116, as added Pub. L. 110–204, § 7, Apr. 24, 2008, 122 Stat. 711; amended Pub. L. 110–237, § 1(a)(7), May 27, 2008, 122 Stat. 1557; Pub. L. 113–240, § 9, Dec. 18, 2014, 128 Stat. 2855.)

AMENDMENTS

2014—Subsec. (a)(1)(C) to (E). Pub. L. 113–240, § 9(1), added subpars. (C) and (D) and redesignated former subpar. (C) as (E).

Subsec. (c). Pub. L. 113–240, § 9(2), substituted ''section 283 of this title'' for ''section 403 of the National Institutes of Health Reform Act of 2006''.

2008—Subsec. (a)(1)(B). Pub. L. 110–237 substituted '', or'' for ''and or''.

§ 300b–16. Authorization of appropriations for newborn screening programs and activities

There are authorized to be appropriated—

(1) to carry out sections 300b–8, 300b–9, 300b–10, and 300b–11 of this title, $11,900,000 for each of fiscal years 2015 through 2019; and

(2) to carry out section 300b–12 of this title, $8,000,000 for each of fiscal years 2015 through 2019.

(July 1, 1944, ch. 373, title XI, § 1117, as added Pub. L. 113–240, § 10, Dec. 18, 2014, 128 Stat. 2856.)

§ 300b–17. Report by Secretary

(1) In general

The Secretary of Health and Human Services shall—

(A) not later than 1 year after December 18, 2014, 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 activities related to—

(i) newborn screening; and

(ii) screening children who have or are at risk for heritable disorders; and

(B) not less than every 2 years, submit to such committees an updated version of such report.

(2) Contents

The report submitted under this section shall contain a description of—

(A) the ongoing activities under sections 300b–8, 300b–9, and 300b–11 through 300b–14 of this title; and

(B) the amounts expended on such activities.

(Pub. L. 113–240, §11(b), Dec. 18, 2014, 128 Stat. 2856.)

CODIFICATION

Section was enacted as part of the Newborn Screening Saves Lives Reauthorization Act of 2014, and not as part of the Public Health Service Act which comprises this chapter.

PRIOR PROVISIONS

Prior sections 300c to 300c–4 were repealed by Pub. L. 94–278, title IV, §403(a), Apr. 22, 1976, 90 Stat. 407.

Section 300c, act July 1, 1944, ch. 373, title XI, §1111, as added Aug. 29, 1972, Pub. L. 92–414, §3, 86 Stat. 650, authorized Secretary to make grants and enter contracts with public and private entities for establishment of screening, treatment, and counseling programs with respect to Cooley's Anemia.

Section 300c–1, act July 1, 1944, ch. 373, title XI, §1112, as added Aug. 29, 1972, Pub. L. 92–414, §3, 86 Stat. 651, required that any participation by an individual in any Cooley's Anemia programs should be on a purely voluntary basis.

Section 300c–2, act July 1, 1944, ch. 373, title XI, §1113, as added Aug. 29, 1972, Pub. L. 92–414, §3, 86 Stat. 651, provided for making of grant upon application to Secretary and listed certain requirements to be met by applicant.

Section 300c–3, act July 1, 1944, ch. 373, title XI, §1114, as added Aug. 29, 1972, Pub. L. 92–414, §3, 86 Stat. 652, authorized Secretary to establish a program with Public Health Service to provide for screening, counseling, and treatment with respect to Cooley's Anemia.

Section 300c–4, act July 1, 1944, ch. 373, title XI, §1115, as added Aug. 29, 1972, Pub. L. 92–414, §3, 86 Stat. 652, provided for Secretary's submission of a report to President for transmittal to Congress annually.

PART B—SUDDEN INFANT DEATH SYNDROME

CODIFICATION

Pub. L. 94–278, title IV, §403(b)(2), Apr. 22, 1976, 90 Stat. 409, redesignated part C heading as part B heading.

§ 300c–11. Repealed. Pub. L. 97–35, title XXI, § 2193(b)(1), Aug. 13, 1981, 95 Stat. 827

Section, act July 1, 1944, ch. 373, title XI, §1121, as added Apr. 22, 1974, Pub. L. 93–270, §3(a), 88 Stat. 91; amended Apr. 22, 1976, Pub. L. 94–278, title IV, §403(b)(1), 90 Stat. 409; S. Res. 4, Feb. 4, 1977; Aug. 1, 1977, Pub. L. 95–83, title III, §306(a), 91 Stat. 389; Dec. 19, 1977, Pub. L. 95–215, §8(a), 91 Stat. 1507; Nov. 8, 1978, Pub. L. 95–613, §2, 92 Stat. 3094; Dec. 12, 1979, Pub. L. 96–142, title II, §202, 93 Stat. 1070; H. Res. 549, Mar. 25, 1980; Aug. 13, 1981, Pub. L. 97–35, title XXI, §2193(a)(1)(C), 95 Stat. 827, related to sudden infant death syndrome counseling, information, educational, and statistical programs.

EFFECTIVE DATE OF 1981 AMENDMENT AND REPEAL, SAVINGS, AND TRANSITIONAL PROVISIONS

For effective date, savings, and transitional provisions relating to the amendment and repeal of this section by Pub. L. 97–35, see section 2194 of Pub. L. 97–35, set out as a note under section 701 of this title.

§ 300c–12. Sudden infant death syndrome research

From the sums appropriated to the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the Secretary shall assure that there are applied to research of the type described in subparagraphs (A) and (B) of subsection (b)(1)[1] of this section such amounts each year as will be adequate, given the leads and findings then available from such research, in order to make maximum feasible progress toward identification of infants at risk of sudden infant death syndrome and prevention of sudden infant death syndrome.

(July 1, 1944, ch. 373, title XI, §1122, as added Pub. L. 96–142, title II, §202, Dec. 12, 1979, 93 Stat. 1072; amended Pub. L. 99–158, §3(a)(6), Nov. 20, 1985, 99 Stat. 879; Pub. L. 103–437, §15(a)(1), Nov. 2, 1994, 108 Stat. 4591; Pub. L. 109–482, title I, §104(b)(2)(B), Jan. 15, 2007, 120 Stat. 3693; Pub. L. 110–154, §1(b)(10), Dec. 21, 2007, 121 Stat. 1827.)

REFERENCES IN TEXT

Subsection (b), referred to in text, was repealed by Pub. L. 109–482, title I, §104(b)(2)(B)(ii), Jan. 15, 2007, 120 Stat. 3693. Prior to repeal, subparagraphs (A) and (B) of subsection (b)(1) read as follows:

''(A) the (i) number of applications approved by the Secretary in the fiscal year reported on for grants and contracts under this chapter for research which relates specifically to sudden infant death syndrome, (ii) total amount requested under such applications, (iii) number of such applications for which funds were provided in such fiscal year, and (iv) total amount of such funds; and

''(B) the (i) number of applications approved by the Secretary in such fiscal year for grants and contracts under this chapter for research which relates generally to sudden infant death syndrome, including high-risk pregnancy and high-risk infancy research which directly relates to sudden infant death syndrome, (ii) relationship of the high-risk pregnancy and high-risk infancy research to sudden infant death syndrome, (iii) total amount requested under such applications, (iv) number of such applications for which funds were provided in such fiscal year, and (v) total amount of such funds.''

AMENDMENTS

2007—Pub. L. 110–154 substituted ''Eunice Kennedy Shriver National Institute of Child Health and Human Development'' for ''National Institute of Child Health and Human Development''.

Pub. L. 109–482 struck out subsec. (a) designation before ''From the sums'' and subsecs. (b) and (c) which related to annual report on data relating to applications for grants and contracts for research on sudden infant death syndrome and annual estimate of amounts requested for such research.

1994—Subsecs. (b)(1), (c). Pub. L. 103–437 substituted ''Energy and Commerce'' for ''Interstate and Foreign Commerce''.

1985—Subsec. (a). Pub. L. 99–158 struck out ''under section 289d of this title'' before '', the Secretary''.

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.

§ 300c–13. Continuing activities related to stillbirth, sudden unexpected infant death and sudden unexplained death in childhood

(a) In general

The Secretary of Health and Human Services shall continue activities related to still birth,

[1] See References in Text note below.