

Pub. L. 93-641, §6, Jan. 4, 1975, 88 Stat. 2275, set out as a note under section 217a of this title, provided that an advisory committee established pursuant to the Public Health Service Act shall terminate at such time as may be specifically prescribed by an Act of Congress enacted after Jan. 4, 1975.

§ 300b-11. Clearinghouse of newborn screening information

(a) In general

The Secretary, acting through the Administrator of the Health Resources and Services Administration (referred to in this part as the “Administrator”), in consultation with the Director of the Centers for Disease Control and Prevention and the Director of the National Institutes of Health, shall establish and maintain a central clearinghouse of current educational and family support and services information, materials, resources, research, and data on newborn screening to—

- (1) enable parents and family members of newborns, health professionals, industry representatives, and other members of the public to increase their awareness, knowledge, and understanding of newborn screening;
- (2) increase awareness, knowledge, and understanding of newborn diseases and screening services for expectant individuals and families;
- (3) maintain current information on quality indicators to measure performance of newborn screening, such as false-positive rates and other quality indicators as determined by the Advisory Committee under section 300b-10 of this title;
- (4) maintain current information on the number of conditions for which screening is conducted in each State; and
- (5) disseminate available evidence-based guidelines related to diagnosis, counseling, and treatment with respect to conditions detected by newborn screening.

(b) Internet availability

The Secretary, acting through the Administrator, shall ensure that the clearinghouse described under subsection (a)—

- (1) is available on the Internet;
- (2) includes an interactive forum;
- (3) is updated on a regular basis, but not less than quarterly; and
- (4) provides—
 - (A) links to Government-sponsored, non-profit, and other Internet websites of laboratories that have demonstrated expertise in newborn screening that supply research-based information on newborn screening tests currently available throughout the United States;
 - (B) information about newborn conditions and screening services available in each State from laboratories certified under subpart 2 of part F of subchapter II, including information about supplemental screening that is available but not required, in the State where the infant is born;
 - (C) current research on both treatable and not-yet treatable conditions for which newborn screening tests are available;
 - (D) the availability of Federal funding for newborn and child screening for heritable

disorders including grants authorized under the Newborn Screening Saves Lives Reauthorization Act of 2014; and

(E) other relevant information as determined appropriate by the Secretary.

(c) Nonduplication

In carrying out activities under this section, the Secretary shall ensure that such activities minimize duplication and supplement, not supplant, existing information sharing efforts.

(July 1, 1944, ch. 373, title XI, §1112, as added Pub. L. 110-204, §5, Apr. 24, 2008, 122 Stat. 708; amended Pub. L. 110-237, §1(a)(4), May 27, 2008, 122 Stat. 1557; Pub. L. 113-240, §5, Dec. 18, 2014, 128 Stat. 2854.)

REFERENCES IN TEXT

The Newborn Screening Saves Lives Reauthorization Act of 2014, referred to in subsec. (b)(4)(D), is Pub. L. 113-240, Dec. 18, 2014, 128 Stat. 2851. For complete classification of this Act to the Code, see Short Title of 2014 Amendment note set out under section 201 of this title and Tables.

AMENDMENTS

2014—Subsec. (a)(3). Pub. L. 113-240, §5(1)(B)(i), substituted “information” for “data”.

Subsec. (a)(4), (5). Pub. L. 113-240, §5(1)(A), (B)(ii), (C), added pars. (4) and (5).

Subsec. (b)(4)(D). Pub. L. 113-240, §5(2), substituted “Newborn Screening Saves Lives Reauthorization Act of 2014” for “Newborn Screening Saves Lives Act of 2008”.

Subsec. (c). Pub. L. 113-240, §5(3), substituted “carrying out activities” for “developing the clearinghouse” and “activities minimize duplication and supplement, not supplant” for “clearinghouse minimizes duplication and supplements, not supplants”.

Subsec. (d). Pub. L. 113-240, §5(4), struck out subsec. (d). Text read as follows: “There are authorized to be appropriated to carry out this section, \$2,500,000 for fiscal year 2009, \$2,531,250 for fiscal year 2010, \$2,562,500 for fiscal year 2011, \$2,593,750 for fiscal year 2012, and \$2,625,000 for fiscal year 2013.”

2008—Subsec. (b)(4)(D). Pub. L. 110-237, §1(a)(4)(A), substituted “2008” for “2007”.

Subsec. (d). Pub. L. 110-237, §1(a)(4)(B), substituted “2009, \$2,531,250 for fiscal year 2010, \$2,562,500 for fiscal year 2011, \$2,593,750 for fiscal year 2012, and \$2,625,000 for fiscal year 2013.” for “2008, \$2,531,250 for fiscal year 2009, \$2,562,500 for fiscal year 2010, \$2,593,750 for fiscal year 2011, and \$2,625,000 for fiscal year 2012.”

§ 300b-12. Laboratory quality and surveillance

(a) In general

The Secretary, acting through the Director of the Centers for Disease Control and Prevention and taking into consideration the expertise of the Advisory Committee on Heritable Disorders in Newborns and Children established under section 300b-10 of this title, shall provide for—

- (1) quality assurance for laboratories involved in screening newborns and children for heritable disorders, including quality assurance for newborn-screening tests, timeliness for processing such tests, performance evaluation services, and technical assistance and technology transfer to newborn screening laboratories to ensure analytic validity and utility of screening tests; and
- (2) appropriate quality control and other performance test materials to evaluate the performance of new screening tools.