§ 280g–5. Public and health care provider education and support services

(a) In general

The Secretary, directly or through the awarding of grants to public or private nonprofit entities, may conduct demonstration projects for the purpose of improving the provision of information on prematurity to health professionals and other health care providers and the public and improving the treatment and outcomes for babies born preterm.

(b) Activities

Activities to be carried out under the demonstration project under subsection (a) may include the establishment of—

(1) programs to test and evaluate various strategies to provide information and education to health professionals, other health care providers, and the public concerning—

(A) the core risk factors for preterm labor and delivery;

(B) medically indicated deliveries before full term;

(C) the importance of preconception and prenatal care, including—

(i) smoking cessation;

(ii) weight maintenance and good nutrition, including folic acid;

(iii) the screening for and the treatment of infections; and

(iv) stress management;

(D) treatments and outcomes for premature infants, including late preterm infants;

(E) the informational needs of families during the stay of an infant in a neonatal intensive care unit; and

(F) utilization of evidence-based strategies to prevent birth injuries;

(2) programs to increase the availability, awareness, and use of pregnancy and post-term information services that provide evidence-based, clinical information through counselors, community outreach efforts, electronic or telephonic communication, or other appropriate means regarding causes associated with prematurity, birth defects, or health risks to a post-term infant;

(3) programs to respond to the informational needs of families during the stay of an infant in a neonatal intensive care unit, during the transition of the infant to the home, and in the event of a newborn death; and

(4) such other programs as the Secretary determines appropriate to achieve the purpose specified in subsection (a).

(c) Authorization of appropriations

There is authorized to be appropriated to carry out this section $1,900,000 for each of fiscal years 2014 through 2018.

(July 1, 1944, ch. 373, title III, § 399Q, as added Pub. L. 109–450, § 4(2), Dec. 22, 2006, 120 Stat. 3342; amended Pub. L. 113–55, title I, § 103(b), Nov. 27, 2013, 127 Stat. 642.)

AMENDMENTS

2013—Subsec. (b)(1). Pub. L. 113–55, § 103(b)(1)(A), added subpars. (A) to (F) and struck out former subpars. (A) to (F) which read as follows:

''(A) the signs of preterm labor, updated as new research results become available;

''(B) the screening for and the treating of infections;

''(c) counseling on optimal weight and good nutrition, including folic acid;

''(D) smoking cessation education and counseling;

''(E) stress management; and

''(F) appropriate prenatal care;''.

Subsec. (b)(2). Pub. L. 113–55, § 103(b)(1)(B), added par. (2) and struck out former par. (2) which read as follows: ''programs to improve the treatment and outcomes for babies born premature, including the use of evidence-based standards of care by health care professionals for pregnant women at risk of preterm labor or other serious complications and for infants born preterm and at a low birthweight;''.

Subsec. (c). Pub. L. 113–55, § 103(b)(2), substituted ''$1,900,000 for each of fiscal years 2014 through 2018.'' for ''$5,000,000 for each of fiscal years 2007 through 2011.''

§ 280g–6. Chronic kidney disease initiatives

(a) In general

The Secretary shall establish pilot projects to—

(1) increase public and medical community awareness (particularly of those who treat patients with diabetes and hypertension) regarding chronic kidney disease, focusing on prevention;

(2) increase screening for chronic kidney disease, focusing on Medicare beneficiaries at risk of chronic kidney disease; and

(3) enhance surveillance systems to better assess the prevalence and incidence of chronic kidney disease.

(b) Scope and duration

(1) Scope

The Secretary shall select at least 3 States in which to conduct pilot projects under this section.

(2) Duration

The pilot projects under this section shall be conducted for a period that is not longer than 5 years and shall begin on January 1, 2009.

(c) Evaluation and report

The Comptroller General of the United States shall conduct an evaluation of the pilot projects conducted under this section. Not later than 12 months after the date on which the pilot projects are completed, the Comptroller General shall submit to Congress a report on the evaluation.

(d) Authorization of appropriations

There are authorized to be appropriated such sums as may be necessary for the purpose of carrying out this section.

(July 1, 1944, ch. 373, title III, § 399R, as added Pub. L. 110–275, title I, § 152(a), July 15, 2008, 122 Stat. 2551.)

CODIFICATION

Another section 399R of act July 1, 1944, ch. 373, as added by Pub. L. 110–373, § 2, Oct. 8, 2008, 122 Stat. 4047, was renumbered section 399S and is classified to section 280g–7 of this title.

Another section 399R of act July 1, 1944, ch. 373, as added by Pub. L. 110–374, § 3, Oct. 8, 2008, 122 Stat. 4051, was renumbered section 399T and is classified to section 280g–8 of this title.

§ 280g–7. Amyotrophic lateral sclerosis registry

(a) Establishment

(1) In general

Not later than 1 year after the receipt of the report described in subsection (b)(2)(A), the Secretary, acting through the Director of the Centers for Disease Control and Prevention, may, if scientifically advisable—

(A) develop a system to collect data on amyotrophic lateral sclerosis (referred to in this section as ''ALS'') and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS, including information with respect to the incidence and prevalence of the disease in the United States; and

(B) establish a national registry for the collection and storage of such data to develop a population-based registry of cases in the United States of ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS.

(2) Purpose

It is the purpose of the registry established under paragraph (1)(B) to—

(A) better describe the incidence and prevalence of ALS in the United States;

(B) examine appropriate factors, such as environmental and occupational, that may be associated with the disease;

(C) better outline key demographic factors (such as age, race or ethnicity, gender, and family history of individuals who are diagnosed with the disease) associated with the disease;

(D) better examine the connection between ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some cases progress to ALS; and

(E) other matters as recommended by the Advisory Committee established under subsection (b).

(b) Advisory Committee

(1) Establishment

Not later than 180 days after October 8, 2008, the Secretary, acting through the Director of the Centers for Disease Control and Prevention, may establish a committee to be known as the Advisory Committee on the National ALS Registry (referred to in this section as the ''Advisory Committee''). The Advisory Committee shall be composed of not more than 27 members to be appointed by the Secretary, acting through the Centers for Disease Control and Prevention, of which—

(A) two-thirds of such members shall represent governmental agencies—

(i) including at least one member representing—

(I) the National Institutes of Health, to include, upon the recommendation of the Director of the National Institutes of Health, representatives from the National Institute of Neurological Disorders and Stroke and the National Institute of Environmental Health Sciences;

(II) the Department of Veterans Affairs;

(III) the Agency for Toxic Substances and Disease Registry; and

(IV) the Centers for Disease Control and Prevention; and

(ii) of which at least one such member shall be a clinician with expertise on ALS and related diseases, an epidemiologist with experience in data registries, a statistician, an ethicist, and a privacy expert (relating to the privacy regulations under the Health Insurance Portability and Accountability Act of 1996); and

(B) one-third of such members shall be public members, including at least one member representing—

(i) national and voluntary health associations;[1]

(ii) patients with ALS or their family members;

(iii) clinicians with expertise on ALS and related diseases;

(iv) epidemiologists with experience in data registries;

(v) geneticists or experts in genetics who have experience with the genetics of ALS or other neurological diseases[2] and

(vi) other individuals with an interest in developing and maintaining the National ALS Registry.

(2) Duties

The Advisory Committee may review information and make recommendations to the Secretary concerning—

(A) the development and maintenance of the National ALS Registry;

(B) the type of information to be collected and stored in the Registry;

(C) the manner in which such data is to be collected;

(D) the use and availability of such data including guidelines for such use; and

(E) the collection of information about diseases and disorders that primarily affect motor neurons that are considered essential to furthering the study and cure of ALS.

(3) Report

Not later than 270 days after the date on which the Advisory Committee is established, the Advisory Committee may submit a report to the Secretary concerning the review conducted under paragraph (2) that contains the recommendations of the Advisory Committee with respect to the results of such review.

(c) Grants

The Secretary, acting through the Director of the Centers for Disease Control and Prevention, may award grants to, and enter into contracts and cooperative agreements with, public or private nonprofit entities for the collection, analysis, and reporting of data on ALS and other motor neuron disorders that can be confused with ALS, misdiagnosed as ALS, and in some

[1] So in original. Probably should be ''national voluntary health associations;''.

[2] So in original. Probably should be followed by a semicolon.