

retary) shall, in consultation with relevant experts or through the Institute of Medicine, study issues related to treatment of PKU and other metabolic disorders for children, adolescents, and adults, and mechanisms to assure access to effective treatment, including special diets, for children and others with PKU and other metabolic disorders. Such mechanisms shall be evidence-based and reflect the best scientific knowledge regarding effective treatment and prevention of disease progression.

“(b) DISSEMINATION OF RESULTS.—Upon completion of the study referred to in subsection (a), the Secretary shall disseminate and otherwise make available the results of the study to interested groups and organizations, including insurance commissioners, employers, private insurers, health care professionals, State and local public health agencies, and State agencies that carry out the Medicaid program under title XIX of the Social Security Act [section 1396 et seq. of this title] or the State children’s health insurance program under title XXI of such Act [section 1397aa et seq. of this title].

“(c) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section such sums as may be necessary for each of the fiscal years 2001 through 2003.”

REVIEW OF DISEASE RESEARCH PROGRAMS OF THE NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES

Section 10 of Pub. L. 99-158 provided that: “The Secretary of Health and Human Services shall conduct an administrative review of the disease research programs of the National Institute of Diabetes and Digestive and Kidney Diseases to determine if any of such programs could be more effectively and efficiently managed by other national research institutes. The Secretary shall complete such review within the one-year period beginning on the date of enactment of this Act [Nov. 20, 1985].”

§ 285c-1. Data systems and information clearinghouses

(a) National Diabetes Data System and National Diabetes Clearinghouse

The Director of the Institute shall (1) establish the National Diabetes Data System for the collection, storage, analysis, retrieval, and dissemination of data derived from patient populations with diabetes, including, where possible, data involving general populations for the purpose of detection of individuals with a risk of developing diabetes, and (2) establish the National Diabetes Information Clearinghouse to facilitate and enhance knowledge and understanding of diabetes on the part of health professionals, patients, and the public through the effective dissemination of information.

(b) National Digestive Diseases Data System and National Digestive Diseases Information Clearinghouse

The Director of the Institute shall (1) establish the National Digestive Diseases Data System for the collection, storage, analysis, retrieval, and dissemination of data derived from patient populations with digestive diseases, including, where possible, data involving general populations for the purpose of detection of individuals with a risk of developing digestive diseases, and (2) establish the National Digestive Diseases Information Clearinghouse to facilitate and enhance knowledge and understanding of digestive diseases on the part of health professionals, patients, and the public through the effective dissemination of information.

(c) National Kidney and Urologic Diseases Data System and National Kidney and Urologic Diseases Information Clearinghouse

The Director of the Institute shall (1) establish the National Kidney and Urologic Diseases Data System for the collection, storage, analysis, retrieval, and dissemination of data derived from patient populations with kidney and urologic diseases, including, where possible, data involving general populations for the purpose of detection of individuals with a risk of developing kidney and urologic diseases, and (2) establish the National Kidney and Urologic Diseases Information Clearinghouse to facilitate and enhance knowledge and understanding of kidney and urologic diseases on the part of health professionals, patients, and the public through the effective dissemination of information.

(July 1, 1944, ch. 373, title IV, §427, as added Pub. L. 99-158, §2, Nov. 20, 1985, 99 Stat. 841.)

§ 285c-2. Division Directors for Diabetes, Endocrinology, and Metabolic Diseases, Digestive Diseases and Nutrition, and Kidney, Urologic, and Hematologic Diseases; functions

(a)(1) In the Institute there shall be a Division Director for Diabetes, Endocrinology, and Metabolic Diseases, a Division Director for Digestive Diseases and Nutrition, and a Division Director for Kidney, Urologic, and Hematologic Diseases. Such Division Directors, under the supervision of the Director of the Institute, shall be responsible for—

(A) developing a coordinated plan (including recommendations for expenditures) for each of the national research institutes within the National Institutes of Health with respect to research and training concerning diabetes, endocrine and metabolic diseases, digestive diseases and nutrition, and kidney, urologic, and hematologic diseases;

(B) assessing the adequacy of management approaches for the activities within such institutes concerning such diseases and nutrition and developing improved approaches if needed;

(C) monitoring and reviewing expenditures by such institutes concerning such diseases and nutrition; and

(D) identifying research opportunities concerning such diseases and nutrition and recommending ways to utilize such opportunities.

(2) The Director of the Institute shall transmit to the Director of NIH the plans, recommendations, and reviews of the Division Directors under subparagraphs (A) through (D) of paragraph (1) together with such comments and recommendations as the Director of the Institute determines appropriate.

(b) The Director of the Institute, acting through the Division Director for Diabetes, Endocrinology, and Metabolic Diseases, the Division Director for Digestive Diseases and Nutrition, and the Division Director for Kidney, Urologic, and Hematologic Diseases, shall—

(1) carry out programs of support for research and training (other than training for which Ruth L. Kirschstein National Research Service Awards may be made under section 288 of this title) in the diagnosis, prevention, and

treatment of diabetes mellitus and endocrine and metabolic diseases, digestive diseases and nutritional disorders, and kidney, urologic, and hematologic diseases, including support for training in medical schools, graduate clinical training, graduate training in epidemiology, epidemiology studies, clinical trials, and interdisciplinary research programs; and

(2) establish programs of evaluation, planning, and dissemination of knowledge related to such research and training.

(July 1, 1944, ch. 373, title IV, § 428, as added Pub. L. 99-158, § 2, Nov. 20, 1985, 99 Stat. 842; amended Pub. L. 103-43, title XX, § 2008(b)(4), June 10, 1993, 107 Stat. 211; Pub. L. 107-206, title I, § 804(c), Aug. 2, 2002, 116 Stat. 874.)

AMENDMENTS

2002—Subsec. (b)(1). Pub. L. 107-206 substituted “Ruth L. Kirschstein National Research Service Awards” for “National Research Service Awards”.

1993—Subsec. (b). Pub. L. 103-43 substituted “the” for “the the” before “Division Director for Diabetes” in introductory provisions.

§ 285c-3. Interagency coordinating committees

(a) Establishment and purpose

For the purpose of—

(1) better coordination of the research activities of all the national research institutes relating to diabetes mellitus, digestive diseases, and kidney, urologic, and hematologic diseases; and

(2) coordinating those aspects of all Federal health programs and activities relating to such diseases to assure the adequacy and technical soundness of such programs and activities and to provide for the full communication and exchange of information necessary to maintain adequate coordination of such programs and activities;

the Secretary shall establish a Diabetes Mellitus Interagency Coordinating Committee, a Digestive Diseases Interagency Coordinating Committee, and a Kidney, Urologic, and Hematologic Diseases Coordinating Committee (hereafter in this section individually referred to as a “Committee”).

(b) Membership; chairman; meetings

Each Committee shall be composed of the Directors of each of the national research institutes and divisions involved in research with respect to the diseases for which the Committee is established, the Division Director of the Institute for the diseases for which the Committee is established, the Under Secretary for Health of the Department of Veterans Affairs, and the Assistant Secretary of Defense for Health Affairs (or the designees of such officers) and shall include representation from all other Federal departments and agencies whose programs involve health functions or responsibilities relevant to such diseases, as determined by the Secretary. Each Committee shall be chaired by the Director of NIH (or the designee of the Director). Each Committee shall meet at the call of the chairman, but not less often than four times a year.

(July 1, 1944, ch. 373, title IV, § 429, as added Pub. L. 99-158, § 2, Nov. 20, 1985, 99 Stat. 843; amended

Pub. L. 100-527, § 10(4), Oct. 25, 1988, 102 Stat. 2641; Pub. L. 102-405, title III, § 302(e)(1), Oct. 9, 1992, 106 Stat. 1985; Pub. L. 108-362, § 3, Oct. 25, 2004, 118 Stat. 1703; Pub. L. 109-482, title I, § 104(b)(1)(H), Jan. 15, 2007, 120 Stat. 3693.)

AMENDMENTS

2007—Subsecs. (c), (d). Pub. L. 109-482 struck out subsecs. (c) and (d) which required an annual report detailing the work of the Committee in carrying out subsec. (a) and an annual assessment on Federal pancreatic islet cell transplantation, respectively.

2004—Subsec. (d). Pub. L. 108-362 added subsec. (d).

1992—Subsec. (b). Pub. L. 102-405 substituted “Under Secretary for Health of the Department of Veterans Affairs” for “Chief Medical Director of the Department of Veterans Affairs”.

1988—Subsec. (b). Pub. L. 100-527 substituted “Chief Medical Director of the Department of Veterans Affairs” for “Chief Medical Director of the Veterans’ Administration”.

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.

EFFECTIVE DATE OF 1988 AMENDMENT

Amendment by Pub. L. 100-527 effective Mar. 15, 1989, see section 18(a) of Pub. L. 100-527, set out as a Department of Veterans Affairs Act note under section 301 of Title 38, Veterans’ Benefits.

§ 285c-4. Advisory boards

(a) Establishment

The Secretary shall establish in the Institute the National Diabetes Advisory Board, the National Digestive Diseases Advisory Board, and the National Kidney and Urologic Diseases Advisory Board (hereafter in this section individually referred to as an “Advisory Board”).

(b) Membership; ex officio members

Each Advisory Board shall be composed of eighteen appointed members and nonvoting ex officio members as follows:

(1) The Secretary shall appoint—

(A) twelve members from individuals who are scientists, physicians, and other health professionals, who are not officers or employees of the United States, and who represent the specialties and disciplines relevant to the diseases with respect to which the Advisory Board is established; and

(B) six members from the general public who are knowledgeable with respect to such diseases, including at least one member who is a person who has such a disease and one member who is a parent of a person who has such a disease.

Of the appointed members at least five shall by virtue of training or experience be knowledgeable in the fields of health education, nursing, data systems, public information, and community program development.

(2)(A) The following shall be ex officio members of each Advisory Board:

(i) The Assistant Secretary for Health, the Director of NIH, the Director of the National Institute of Diabetes and Digestive and Kidney Diseases, the Director of the Centers for Disease Control and Prevention, the Under