(B) securing funding for the Partnership from Federal and non-Federal governmental sources, foundations, and private individuals; and

(4) provides an assurance that the entity will not accept funding for a Partnership project from any organization that manufactures or distributes products regulated by the Food and Drug Administration unless the entity provides assurances in its agreement with the Secretary that the results of the project will not be influenced by any source of funding.

(c) Gifts

(1) In general

The Partnership may solicit and accept gifts, grants, and other donations, establish accounts, and invest and expend funds in support of basic research and research associated with phase 3 clinical trials conducted with respect to investigational drugs that are the subjects of expanded access requests under section 360bbb of title 21.

(2) Use

In addition to any amounts appropriated for purposes of carrying out this section, the Partnership may use, without further appropriation, any funds derived from a gift, grant, or other donation accepted pursuant to paragraph (1).

(Pub. L. 117–79, § 3, Dec. 23, 2021, 135 Stat. 1535.)

Editorial Notes

REFERENCES IN TEXT

Section 1001 of title 20, referred to in subsec. (b)(1)(A), was in the original ''section 1001 of the Higher Education Act of 1965'' and was translated as if it had read ''section 101 of the Higher Education Act of 1965'' to reflect the probable intent of Congress. Section 101 of the Higher Education Act of 1965 is classified to section 1001 of Title 20, Education, and defines ''institution of higher education''.

CODIFICATION

Section was enacted as part of the Accelerating Access to Critical Therapies for ALS Act, and not as part of the Public Health Service Act which comprises this chapter.

§ 280g–8. Support for patients receiving a positive diagnosis of Down syndrome or other prenatally or postnatally diagnosed conditions

(a) Definitions

In this section:

(1) Down syndrome

The term ''Down syndrome'' refers to a chromosomal disorder caused by an error in cell division that results in the presence of an extra whole or partial copy of chromosome 21.

(2) Health care provider

The term ''health care provider'' means any person or entity required by State or Federal law or regulation to be licensed, registered, or certified to provide health care services, and who is so licensed, registered, or certified.

(3) Postnatally diagnosed condition

The term ''postnatally diagnosed condition'' means any health condition identified during the 12-month period beginning at birth.

(4) Prenatally diagnosed condition

The term ''prenatally diagnosed condition'' means any fetal health condition identified by prenatal genetic testing or prenatal screening procedures.

(5) Prenatal test

The term ''prenatal test'' means diagnostic or screening tests offered to pregnant women seeking routine prenatal care that are administered on a required or recommended basis by a health care provider based on medical history, family background, ethnic background, previous test results, or other risk factors.

(b) Information and support services

(1) In general

The Secretary, acting through the Director of the National Institutes of Health, the Director of the Centers for Disease Control and Prevention, or the Administrator of the Health Resources and Services Administration, may authorize and oversee certain activities, including the awarding of grants, contracts or cooperative agreements to eligible entities, to—

(A) collect, synthesize, and disseminate current evidence-based information relating to Down syndrome or other prenatally or postnatally diagnosed conditions; and

(B) coordinate the provision of, and access to, new or existing supportive services for patients receiving a positive diagnosis for Down syndrome or other prenatally or postnatally diagnosed conditions, including—

(i) the establishment of a resource telephone hotline accessible to patients receiving a positive test result or to the parents of newly diagnosed infants with Down syndrome and other diagnosed conditions;

(ii) the expansion and further development of the National Dissemination Center for Children with Disabilities, so that such Center can more effectively conduct outreach to new and expecting parents and provide them with up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes;

(iii) the expansion and further development of national and local peer-support programs, so that such programs can more effectively serve women who receive a positive diagnosis for Down syndrome or other prenatal conditions or parents of infants with a postnatally diagnosed condition;

(iv) the establishment of a national registry, or network of local registries, of families willing to adopt newborns with Down syndrome or other prenatally or postnatally diagnosed conditions, and links to adoption agencies willing to place babies with Down syndrome or other prenatally or postnatally diagnosed conditions, with families willing to adopt; and

(v) the establishment of awareness and education programs for health care providers who provide, interpret, or inform

parents of the results of prenatal tests for Down syndrome or other prenatally or postnatally diagnosed conditions, to patients, consistent with the purpose described in section 2(b)(1)[1] of the Prenatally and Postnatally Diagnosed Conditions Awareness Act.

(2) Eligible entity

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

(A) a State or a political subdivision of a State;

(B) a consortium of 2 or more States or political subdivisions of States;

(C) a territory;

(D) a health facility or program operated by or pursuant to a contract with or grant from the Indian Health Service; or

(E) any other entity with appropriate expertise in prenatally and postnatally diagnosed conditions (including nationally recognized disability groups), as determined by the Secretary.

(3) Distribution

In distributing funds under this subsection, the Secretary shall place an emphasis on funding partnerships between health care professional groups and disability advocacy organizations.

(c) Provision of information to providers

(1) In general

A grantee under this section shall make available to health care providers of parents who receive a prenatal or postnatal diagnosis the following:

(A) Up-to-date, evidence-based, written information concerning the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes.

(B) Contact information regarding support services, including information hotlines specific to Down syndrome or other prenatally or postnatally diagnosed conditions, resource centers or clearinghouses, national and local peer support groups, and other education and support programs as described in subsection (b)(2).

(2) Informational requirements

Information provided under this subsection shall be—

(A) culturally and linguistically appropriate as needed by women receiving a positive prenatal diagnosis or the family of infants receiving a postnatal diagnosis; and

(B) approved by the Secretary.

(d) Report

Not later than 2 years after October 8, 2008, the Government Accountability Office shall submit a report to Congress concerning the effectiveness of current healthcare and family support programs serving as resources for the families of children with disabilities.

(July 1, 1944, ch. 373, title III, § 399T, formerly § 399R, as added Pub. L. 110–374, § 3, Oct. 8, 2008, 122 Stat. 4051; renumbered § 399T, Pub. L. 111–148, title IV, § 4003(b)(2)(B), Mar. 23, 2010, 124 Stat. 544.)

[1] See References in Text note below.

Editorial Notes

REFERENCES IN TEXT

Section 2(b)(1) of the Prenatally and Postnatally Diagnosed Conditions Awareness Act, referred to in subsec. (b)(1)(B)(v), probably means section 2(1) of that Act, Pub. L. 110–374, which is set out as a note under this section.

Statutory Notes and Related Subsidiaries

PURPOSES

Pub. L. 110–374, § 2, Oct. 8, 2008, 122 Stat. 4051, provided that: ''It is the purpose of this Act [enacting this section and provisions set out as a note under section 201 of this title] to—

''(1) increase patient referrals to providers of key support services for women who have received a positive diagnosis for Down syndrome, or other prenatally or postnatally diagnosed conditions, as well as to provide up-to-date information on the range of outcomes for individuals living with the diagnosed condition, including physical, developmental, educational, and psychosocial outcomes;

''(2) strengthen existing networks of support through the Centers for Disease Control and Prevention, the Health Resources and Services Administration, and other patient and provider outreach programs; and

''(3) ensure that patients receive up-to-date, evidence-based information about the accuracy of the test.''

§ 280g–9. Programs to improve quality of life for persons with paralysis and other physical disabilities

(a) In general

The Secretary of Health and Human Services (in this section referred to as the ''Secretary'') may study the unique health challenges associated with paralysis and other physical disabilities and carry out projects and interventions to improve the quality of life and long-term health status of persons with paralysis and other physical disabilities. The Secretary may carry out such projects directly and through awards of grants or contracts.

(b) Certain activities

Activities under subsection (a) may include—

(1) the development of a national paralysis and physical disability quality of life action plan, to promote health and wellness in order to enhance full participation, independent living, self-sufficiency, and equality of opportunity in partnership with voluntary health agencies focused on paralysis and other physical disabilities, to be carried out in coordination with the State-based Disability and Health Program of the Centers for Disease Control and Prevention;

(2) support for programs to disseminate information involving care and rehabilitation options and quality of life grant programs supportive of community-based programs and support systems for persons with paralysis and other physical disabilities;

(3) in collaboration with other centers and national voluntary health agencies, the estab-