

106TH CONGRESS
2D SESSION

H. R. 5260

To amend the Public Health Service Act to provide for a national system of screening newborn infants for hereditary disorders, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 21, 2000

Mr. PALLONE (for himself, Mr. FROST, Mr. BROWN of Ohio, Ms. CARSON, Mr. MURTHA, and Mr. WAXMAN) introduced the following bill; which was referred to the Committee on Commerce

A BILL

To amend the Public Health Service Act to provide for a national system of screening newborn infants for hereditary disorders, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Hereditary Disorders
3 Newborn Screening Act of 2000”.

4 **SEC. 2. PROGRAM TO IMPROVE THE ABILITY OF STATES TO**
5 **PROVIDE NEWBORN AND CHILD SCREENING**
6 **FOR HERITABLE DISORDERS.**

7 Part A of title XI of the Public Health Service Act
8 (42 U.S.C. 300b–1 et seq.) is amended by adding at the
9 end the following:

10 **“SEC. 1108. IMPROVED NEWBORN AND CHILD SCREENING**
11 **FOR HERITABLE DISORDERS.**

12 “(a) IN GENERAL.—The Secretary, acting through
13 the Administrator of the Health Resources and Services
14 Administration, shall award grants to eligible entities to
15 enhance, improve or expand the ability of State and local
16 public health agencies to provide screening, counseling or
17 preventive care services to newborns and children having
18 or at risk for heritable disorders.

19 “(b) USE OF FUNDS.—Amounts provided under a
20 grant awarded under subsection (a) shall be used to—

21 “(1) establish, expand, or improve systems or
22 programs to provide screening, counseling, testing or
23 specialty services for newborns and children at risk
24 for heritable disorders;

1 “(2) establish, expand, or improve programs or
2 services to reduce mortality or morbidity from heri-
3 table disorders;

4 “(3) establish, expand, or improve systems or
5 programs to provide information and counseling on
6 available therapies for newborns and children with
7 heritable disorders;

8 “(4) improve the access of medically under-
9 served populations to screening, counseling, testing
10 and specialty services for newborns and children
11 having or at risk for heritable disorders; or

12 “(5) conduct such other activities as may be
13 necessary to enable newborns and children having or
14 at risk for heritable disorders to receive screening,
15 counseling, testing or specialty services, regardless of
16 income, race, color, religion, sex, national origin,
17 age, or disability.

18 “(c) ELIGIBLE ENTITIES.—To be eligible to receive
19 a grant under subsection (a) an entity shall—

20 “(1) be a State or political subdivision of a
21 State, or a consortium of 2 or more States or polit-
22 ical subdivisions of States; and

23 “(2) prepare and submit to the Secretary an
24 application that includes—

1 “(A) a plan to use amounts awarded under
2 the grant to meet specific health status goals
3 and objectives relative to heritable disorders, in-
4 cluding attention to needs of medically under-
5 served populations;

6 “(B) a plan for the collection of outcome
7 data or other methods of evaluating the degree
8 to which amounts awarded under this grant will
9 be used to achieve the goals and objectives iden-
10 tified under subparagraph (A);

11 “(C) a plan for monitoring and ensuring
12 the quality of services provided under the grant;

13 “(D) an assurance that amounts awarded
14 under the grant will be used only to implement
15 the approved plan for the State;

16 “(E) an assurance that the provision of
17 services under the plan is coordinated with serv-
18 ices provided under programs implemented in
19 the State under titles V, XVIII, XIX, XX, or
20 XXI of the Social Security Act (subject to Fed-
21 eral regulations applicable to such programs) so
22 that the coverage of services under such titles
23 is not substantially diminished by the use of
24 granted funds; and

1 “(F) such other information determined by
2 the Secretary to be necessary.

3 “(d) LIMITATION.—An eligible entity may not use
4 amounts received under this section to—

5 “(1) provide cash payments to or on behalf of
6 affected individuals;

7 “(2) provide inpatient services;

8 “(3) purchase land or make capital improve-
9 ments to property; or

10 “(4) provide for proprietary research or train-
11 ing.

12 “(e) VOLUNTARY PARTICIPATION.—The participa-
13 tion by any individual in any program or portion thereof
14 established or operated with funds received under this sec-
15 tion shall be wholly voluntary and shall not be a pre-
16 requisite to eligibility for or receipt of any other service
17 or assistance from, or to participation in, another Federal
18 or State program.

19 “(f) SUPPLEMENT NOT SUPPLANT.—Funds appro-
20 priated under this section shall be used to supplement and
21 not supplant other Federal, State, and local public funds
22 provided for activities of the type described in this section.

23 “(g) PUBLICATION.

24 “(1) IN GENERAL.—An application submitted
25 under subsection (c)(2) shall be made public by the

1 State in such a manner as to facilitate comment
2 from any person, including through hearings and
3 other methods used to facilitate comments from the
4 public.

5 “(2) COMMENTS.—Comments received by the
6 State after the publication described in paragraph
7 (1) shall be addressed in the application submitted
8 under subsection (c)(2).

9 “(h) TECHNICAL ASSISTANCE.—The Secretary shall
10 provide to entities receiving grants under subsection (a)
11 such technical assistance as may be necessary to ensure
12 the quality of programs conducted under this section.

13 “(i) AUTHORIZATION OF APPROPRIATIONS.—There
14 are authorized to be appropriated to carry out this section,
15 such sums as may be necessary for each of the fiscal years
16 2001 through 2011.

17 **“SEC. 1109. EVALUATING THE EFFECTIVENESS OF NEW-**
18 **BORN AND CHILD SCREENING PROGRAMS.**

19 “(a) IN GENERAL.—The Secretary shall award
20 grants to eligible entities to provide for the conduct of
21 demonstration programs to evaluate the effectiveness of
22 screening, counseling or preventive care services in reduc-
23 ing the morbidity and mortality caused by heritable dis-
24 orders in newborns and children.

1 “(b) DEMONSTRATION PROGRAMS.—A demonstra-
2 tion program conducted under a grant under this section
3 shall be designed to evaluate and assess, within the juris-
4 diction of the entity receiving such grant—

5 “(1) the effectiveness of screening, counseling,
6 testing or specialty services for newborns and chil-
7 dren at risk for heritable disorders in reducing the
8 morbidity and mortality associated with such dis-
9 orders;

10 “(2) the effectiveness of screening, counseling,
11 testing or specialty services in accurately and reli-
12 ably diagnosing heritable disorders in newborns and
13 children; or

14 “(3) the availability of screening, counseling,
15 testing or specialty services for newborns and chil-
16 dren at risk for heritable disorders.

17 “(c) ELIGIBLE ENTITIES.—To be eligible to receive
18 a grant under subsection (a) an entity shall be a State
19 or political subdivision of a State, or a consortium of 2
20 or more States or political subdivisions of States.

21 **“SEC. 1110. ADVISORY COMMITTEE ON HERITABLE DIS-**
22 **ORDERS IN NEWBORNS AND CHILDREN.**

23 “(a) ESTABLISHMENT.—The Secretary shall estab-
24 lish an advisory committee to be known as the ‘Advisory
25 Committee on Heritable Disorders in Newborns and Chil-

1 dren' (referred to in this section as the 'Advisory Com-
2 mittee').

3 “(b) DUTIES.—The Advisory Committee shall—

4 “(1) provide advice and recommendations to the
5 Secretary concerning grants and projects awarded or
6 funded under section 1108;

7 “(2) provide technical information to the Sec-
8 retary for the development of policies and priorities
9 for the administration of grants under section 1108;
10 and

11 “(3) provide such recommendations, advice or
12 information as may be necessary to enhance, expand
13 or improve the ability of the Secretary to reduce the
14 mortality or morbidity from heritable disorders.

15 “(c) MEMBERSHIP.—

16 “(1) IN GENERAL.—The Secretary shall appoint
17 not to exceed 15 members to the Advisory Com-
18 mittee. In appointing such members, the Secretary
19 shall ensure that the total membership of the Advi-
20 sory Committee is an odd number.

21 “(2) REQUIRED MEMBERS.—The Secretary
22 shall appoint to the Advisory Committee under para-
23 graph (1)—

24 “(A) the Administrator of the Health Re-
25 sources and Services Administration;

1 “(B) the Director of the Centers for Dis-
2 ease Control and Prevention;

3 “(C) the Director of the National Insti-
4 tutes of Health;

5 “(D) the Director of the Agency for
6 Healthcare Research and Quality;

7 “(E) medical or scientific professionals
8 with special expertise in heritable disorders, or
9 in providing screening, counseling, testing or
10 specialty services for newborns and children at
11 risk for heritable disorders;

12 “(F) members of the public having special
13 expertise about or concern with heritable dis-
14 orders; and

15 “(G) representatives from such Federal
16 agencies, public health constituencies, and med-
17 ical professional societies as determined to be
18 necessary by the Secretary, to fulfill the duties
19 of the Advisory Committee, as established
20 under subsection (b).”.

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