

**AMENDMENT IN THE NATURE OF A SUBSTITUTE
TO H.R. 3112
OFFERED BY MR. PALLONE OF NEW JERSEY**

Strike all after the enacting clause and insert the following:

1 SECTION 1. SHORT TITLE.

2 This Act may be cited as the “Prenatally and
3 Postnatally Diagnosed Conditions Awareness Act”.

4 SEC. 2. PURPOSES.

5 It is the purpose of this Act to—

6 (1) increase patient referrals to providers of key
7 support services for pregnant women who have re-
8 ceived a positive diagnosis for Down syndrome or
9 other prenatally diagnosed condition and parents of
10 infants who have received a positive diagnosis for a
11 postnatally diagnosed condition, as well as to provide
12 up-to-date information on the range of outcomes for
13 individuals living with the diagnosed condition, in-
14 cluding physical, developmental, educational, and
15 psychosocial outcomes;

16 (2) strengthen existing networks of support
17 through the Centers for Disease Control and Preven-
18 tion, the Health Resources and Services Administra-

1 tion, and other patient and provider outreach pro-
2 grams; and

3 (3) ensure that patients receive up-to-date, evi-
4 dence-based information about the accuracy of the
5 test.

6 **SEC. 3. AMENDMENT TO THE PUBLIC HEALTH SERVICE**
7 **ACT.**

8 Part P of title III of the Public Health Service Act
9 (42 U.S.C. 280g et seq.) is amended by adding at the end
10 the following:

11 **“SEC. 399R. SUPPORT FOR PATIENTS RECEIVING A POSI-**
12 **TIVE DIAGNOSIS OF DOWN SYNDROME OR**
13 **OTHER PRENATALLY OR POSTNATALLY DIAG-**
14 **NOSED CONDITIONS.**

15 “(a) DEFINITIONS.—In this section:

16 “(1) DOWN SYNDROME.—The term ‘Down syn-
17 drome’ refers to a chromosomal disorder caused by
18 an error in cell division that results in the presence
19 of an extra whole or partial copy of chromosome 21.

20 “(2) HEALTH CARE PROVIDER.—The term
21 ‘health care provider’ means any person or entity re-
22 quired by State or Federal law or regulation to be
23 licensed, registered, or certified to provide health
24 care services, and who is so licensed, registered, or
25 certified.

1 “(3) POSTNATALLY DIAGNOSED CONDITION.—

2 The term ‘postnatally diagnosed condition’ means
3 any health condition identified during the 12-month
4 period beginning at birth.

5 “(4) PRENATALLY DIAGNOSED CONDITION.—

6 The term ‘prenatally diagnosed condition’ means any
7 fetal health condition identified by prenatal genetic
8 testing or prenatal screening procedures.

9 “(5) PRENATAL TEST.—The term ‘prenatal
10 test’ means diagnostic or screening tests offered to
11 pregnant women seeking routine prenatal care that
12 are administered on a required or recommended
13 basis by a health care provider based on medical his-
14 tory, family background, ethnic background, pre-
15 vious test results, or other risk factors.

16 “(b) INFORMATION AND SUPPORT SERVICES.—

17 “(1) IN GENERAL.—The Secretary, acting
18 through the Director of the National Institutes of
19 Health, the Director of the Centers for Disease Con-
20 trol and Prevention, or the Administrator of the
21 Health Resources and Services Administration, may
22 authorize and oversee certain activities, including the
23 awarding of grants, contracts, or cooperative agree-
24 ments to eligible entities, to—

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

5 “(B) coordinate the provision of, and ac-
6 cess to, new or existing supportive services for
7 patients receiving a positive diagnosis for Down
8 syndrome or other prenatally or postnatally di-
9 agnosed conditions, including—

10 “(i) the establishment of a resource
11 telephone hotline accessible to patients re-
12 ceiving a positive test result or to the par-
13 ents of newly diagnosed infants with Down
14 syndrome and other diagnosed conditions;

15 “(ii) the expansion and further devel-
16 opment of the National Dissemination
17 Center for Children with Disabilities, so
18 that such Center can more effectively con-
19 duct outreach to new and expecting par-
20 ents and provide them with up-to-date in-
21 formation on the range of outcomes for in-
22 dividuals living with the diagnosed condi-
23 tion, including physical, developmental,
24 educational, and psychosocial outcomes;

1 “(iii) the expansion and further devel-
2 opment of national and local peer-support
3 programs, so that such programs can more
4 effectively serve pregnant women who re-
5 ceive a positive diagnosis for Down syn-
6 drome or other prenatal conditions or par-
7 ents of infants with a postnatally diag-
8 nosed condition;

9 “(iv) the establishment of a national
10 registry, or network of local registries, of
11 families willing to adopt newborns with
12 Down syndrome or other prenatally or
13 postnatally diagnosed conditions, and links
14 to adoption agencies willing to place babies
15 with Down syndrome or other prenatally or
16 postnatally diagnosed conditions, with fam-
17 ilies willing to adopt; and

18 “(v) the establishment of awareness
19 and education programs for health care
20 providers who provide, interpret, or inform
21 parents of the results of prenatal tests for
22 Down syndrome or other prenatally or
23 postnatally diagnosed conditions, to pa-
24 tients, consistent with the purpose de-
25 scribed in section 2(1) of the Prenatally

1 and Postnatally Diagnosed Conditions
2 Awareness Act.

3 “(2) ELIGIBLE ENTITY.—In this subsection, the
4 term ‘eligible entity’ means—

5 “(A) a State or a political subdivision of a
6 State;

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

9 “(C) a territory;

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

13 “(E) any other entity with appropriate ex-
14 pertise in prenatally and postnatally diagnosed
15 conditions (including nationally recognized dis-
16 ability groups), as determined by the Secretary.

17 “(3) DISTRIBUTION.—In distributing funds
18 under this subsection, the Secretary shall place an
19 emphasis on funding partnerships between health
20 care professional groups and disability advocacy or-
21 ganizations.

22 “(c) PROVISION OF INFORMATION TO PROVIDERS.—

23 “(1) IN GENERAL.—A grantee under this sec-
24 tion shall make available to health care providers of

1 parents who receive a prenatal diagnosis or post-
2 natal diagnosis the following:

3 “(A) Up-to-date, evidence-based, written
4 information concerning the range of outcomes
5 for individuals living with the diagnosed condi-
6 tion, including physical, developmental, edu-
7 cational, and psychosocial outcomes.

8 “(B) Contact information regarding sup-
9 port services, including information hotlines
10 specific to Down syndrome or other prenatally
11 or postnatally diagnosed conditions, resource
12 centers or clearinghouses, national and local
13 peer support groups, and other education and
14 support programs as described in subsection
15 (b)(2).

16 “(2) INFORMATIONAL REQUIREMENTS.—Infor-
17 mation provided under this subsection shall be—

18 “(A) culturally and linguistically appro-
19 priate as needed by pregnant women receiving
20 a positive prenatal diagnosis or the family of in-
21 fants receiving a postnatal diagnosis; and

22 “(B) approved by the Secretary.

23 “(d) REPORT.—Not later than 2 years after the date
24 of the enactment of this section, the Government Account-
25 ability Office shall submit to Congress a report concerning

1 the effectiveness of health care and family support pro-
2 grams, in existence as of the date of the enactment of this
3 section, serving as resources for the families of children
4 with disabilities.

5 “(e) AUTHORIZATION OF APPROPRIATIONS.—There
6 is authorized to be appropriated to carry out this section,
7 \$5,000,000 for each of the fiscal years 2009 through
8 2013.”.

Amend the title so as to read “A Bill to amend the
Public Health Service Act to increase the provision of sci-
entifically sound information and support services to
pregnant women receiving a positive test diagnosis for
Down syndrome or other prenatally diagnosed condition
and parents of infants receiving a positive test diagnosis
for postnatally diagnosed conditions.”.

