

105TH CONGRESS
1ST SESSION

H. R. 1114

To provide surveillance, research, and services aimed at prevention of birth defects, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 18, 1997

Mr. ORTIZ (for himself and Mr. BONILLA) introduced the following bill; which was referred to the Committee on Commerce

A BILL

To provide surveillance, research, and services aimed at prevention of birth defects, 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,*

3 **SECTION 1. SHORT TITLE; FINDINGS.**

4 (a) SHORT TITLE.—This Act may be cited as the
5 “Birth Defects Prevention Act of 1997”.

6 (b) FINDINGS.—The Congress makes the following
7 findings:

8 (1) Birth defects are the leading cause of infant
9 mortality, directly responsible for one out of every
10 five infant deaths.

1 (2) Thousands of the 150,000 infants born with
2 a serious birth defect annually face a lifetime of
3 chronic disability and illness.

4 (3) Birth defects threaten the lives of infants of
5 all racial and ethnic backgrounds. However, some
6 conditions pose excess risks for certain populations.
7 For example, compared to all infants born in the
8 United States, Hispanic-American infants are more
9 likely to be born with anencephaly spina bifida and
10 other neural tube defects and African-American in-
11 fants are more likely to be born with sickle-cell ane-
12 mia.

13 (4) Birth defects can be caused by exposure to
14 environmental hazards, adverse health conditions
15 during pregnancy, or genetic mutations. Prevention
16 efforts are slowed by lack of information about the
17 number and causes of birth defects. Outbreaks of
18 birth defects may go undetected because surveillance
19 and research efforts are underdeveloped and poorly
20 coordinated.

21 **SEC. 2. BIRTH DEFECTS PREVENTION AND RESEARCH PRO-**
22 **GRAM.**

23 Part B of title III of the Public Health Service Act
24 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
25 tion 317F the following:

1 “(2) AUTHORITY FOR AWARDS.—For purposes
2 of paragraph (1), the Secretary, acting through the
3 Director of the Centers for Disease Control, may
4 award grants or enter into cooperative agreements
5 with State departments of health, universities, or
6 other private, nonprofit entities engaged in research
7 to enable such entities to serve as Centers of Excel-
8 lence for Birth Defects Prevention Research.

9 “(3) APPLICATION.—To be eligible for grants
10 or cooperative agreements under paragraph (2), the
11 entity shall prepare and submit to the Secretary an
12 application at such time, in such manner and con-
13 taining such information as the Secretary may pre-
14 scribe, including assurances that—

15 “(A) the program will collect, analyze, and
16 report birth defects data according to guidelines
17 prescribed by the Director of the Centers for
18 Disease Control;

19 “(B) the program will coordinate States
20 birth defects surveillance and prevention efforts
21 within a region;

22 “(C) education, training, and clinical skills
23 improvement for health professionals aimed at
24 the prevention and control of birth defects will
25 be included in the program activities;

1 “(D) development and evaluation of birth
2 defects prevention strategies will be included in
3 the program activities, as appropriate; and

4 “(E) the program funds will not be used to
5 supplant or duplicate State efforts.

6 “(4) CENTERS TO FOCUS ON RACIAL AND ETH-
7 NIC DISPARITIES IN BIRTH DEFECTS.—One of the
8 Centers of Excellence shall focus on birth defects
9 among ethnic minorities, and shall be located in a
10 standard metropolitan statistical area that has over
11 a 60 percent ethnic minority population, is federally
12 designated as a health professional shortage area,
13 and has an incidence of one or more birth defects
14 more than four times the national average.

15 “(c) CLEARINGHOUSE.—The Centers for Disease
16 Control shall serve as the coordinating agency for birth
17 defects prevention activities through establishment of a
18 clearinghouse for the collection and storage of data and
19 generated from birth defects monitoring programs devel-
20 oped under subsections (a) and (b). Functions of such
21 clearinghouse shall include facilitating the coordination of
22 research and policy development to prevent birth defects.
23 The clearinghouse shall disaggregate data by gender and
24 by racial and ethnic groups, the major Hispanic sub-

1 groups, non-Hispanic whites, African Americans, Native
2 Americans, and Asian Americans.

3 “(d) PREVENTION STRATEGIES.—

4 “(1) IN GENERAL.—The Secretary, acting
5 through the Director of the Centers for Disease
6 Control, shall award grants to or enter into coopera-
7 tive agreements with State departments of health,
8 universities, or other private, or nonprofit entities to
9 enable such entities to develop, evaluate and imple-
10 ment prevention strategies designed to reduce the in-
11 cidence and effects or birth defects including—

12 “(A) demonstration projects for the pre-
13 vention of birth defects, including—

14 “(i) at least one project aimed at en-
15 hancing prevention services in a ‘high-risk
16 area’ that has a proportion of birth to mi-
17 nority women above the national average,
18 is federally designated as a health profes-
19 sional shortage area, and has a high inci-
20 dence of one or more birth defects; and

21 “(ii) at least one outcome research
22 project to study the effectiveness of infant
23 interventions aimed at amelioration of
24 birth defects; and

1 “(B) public information and education pro-
2 grams for the prevention of birth defects, in-
3 cluding but not limited to programs aimed at
4 educating women on the need to consume the
5 daily amount of folic acid (pteroylmon-
6 oglutomic acid) as recommended by the Public
7 Health Service and preventing alcohol and illicit
8 drug use during pregnancy in a manner which
9 is sensitive to the cultural and linguistic context
10 of a given community.

11 “(2) CONSULTATION.—In carrying out pro-
12 grams under this subsection, the Secretary, acting
13 through the Centers for Disease Control and Preven-
14 tion, shall consult with State and local governmental
15 agencies, managed care organizations, nonprofit or-
16 ganizations, physicians, and other health profes-
17 sionals and organizations.

18 “(e) ADVISORY COMMITTEE.—

19 “(1) ESTABLISHMENT OF COMMITTEE.—The
20 Secretary shall establish an Advisory Committee for
21 Birth Defects Prevention (in this subsection referred
22 to as the ‘Committee’). The Committee shall provide
23 advice and recommendations on prevention and ame-
24 lioration of birth defects to the Secretary and the
25 Director of the Centers for Disease Control.

1 “(2) FUNCTIONS.—With respect to birth de-
2 fects prevention, the Committee shall—

3 “(A) make recommendations regarding
4 prevention research and intervention priorities;

5 “(B) study and recommend ways to pre-
6 vent birth defects, with emphasis on emerging
7 technologies;

8 “(C) identify annually the important areas
9 of government and nongovernment cooperation
10 needed to implement prevention strategies;

11 “(D) identify research and prevention
12 strategies which would be successful in address-
13 ing birth defects disparities among the major
14 Hispanic subgroups, non-Hispanic whites, Afri-
15 can Americans, Native Americans, and Asian
16 Americans; and

17 “(E) review and recommend policies and
18 guidance related to birth defects research and
19 prevention.

20 “(3) COMPOSITION.—The Committee shall be
21 composed of 15 members appointed by the Sec-
22 retary, including—

23 “(A) four health professionals, who are not
24 employees of the United States, who have ex-

1 pertise in issues related to prevention of or care
2 for children with birth defects;

3 “(B) two representatives from health pro-
4 fessional associations;

5 “(C) four representatives from voluntary
6 health agencies concerned with conditions lead-
7 ing to birth defects or childhood disability;

8 “(D) five members of the general public, of
9 whom at least three shall be parents of children
10 with birth defects or persons having birth de-
11 fects; and

12 “(E) representatives of the Public Health
13 Service agencies involved in birth defects re-
14 search and prevention programs and represent-
15 atives of other appropriate Federal agencies, in-
16 cluding but not limited to the Department of
17 Education and the Environmental Protection
18 Agency, shall be appointed as ex officio, liaison
19 members for purposes of informing the Com-
20 mittee regarding Federal agency policies and
21 practices;

22 “(4) STRUCTURE.—

23 “(A) TERM OF OFFICE.—Appointed mem-
24 bers of the Committee shall be appointed for a
25 term of office of 3 years, except that of the

1 members first appointed, 5 shall be appointed
2 for a term of 1 year, 5 shall be appointed for
3 a term of 2 years, and 5 shall be appointed for
4 a term of 3 years, as determined by the Sec-
5 retary.

6 “(B) MEETINGS.—The Committee shall
7 meet not less than three times per year and at
8 the call of the chair.

9 “(C) COMPENSATION.—Members of the
10 Committee who are employees of the Federal
11 Government shall serve without compensation.
12 Members of the Committee who are not employ-
13 ees of the Federal Government shall be com-
14 pensated at a rate not to exceed the daily equiv-
15 alent of the rate in effect for grade GS–18.

16 “(f) REPORT.—The Secretary shall prepare and sub-
17 mit to the Committee on Commerce of the House of Rep-
18 resentatives and the Committee on Labor and Human Re-
19 sources of the Senate a biennial report regarding the inci-
20 dence of birth defects, the contribution of birth defects to
21 infant mortality, the outcome of implementation of preven-
22 tion strategies, and identified needs for research and pol-
23 icy development to include information regarding the var-
24 ious racial and ethnic groups, including Hispanic, non-

1 Hispanic whites, African Americans, Native Americans,
2 and Asian Americans.

3 “(g) APPLICABILITY OF PRIVACY LAWS.—The provi-
4 sions of this section shall be subject to the requirements
5 of section 552a of title 5, United States Code. All Federal
6 laws relating to the privacy of information shall apply to
7 the data and information that is collected under this sec-
8 tion.

9 “(h) AUTHORIZATION OF APPROPRIATIONS.—

10 “(1) For the purpose of carrying out sub-
11 sections (a), (b), and (c), there are authorized to be
12 appropriated \$15,000,000 for fiscal year 1998,
13 \$20,000,000 for fiscal year 1999, and such sums as
14 may be necessary for each of the fiscal years 2000
15 and 2001.

16 “(2) For the purpose of carrying out subsection
17 (d), there are authorized to be appropriated
18 \$15,000,000 for fiscal year 1998, \$20,000,000 for
19 fiscal year 1999, and such sums as may be nec-
20 essary for each of the fiscal years 2000 and 2001.

21 “(3) For the purpose of carrying out sub-
22 sections (e) and (f), there are authorized to be ap-
23 propriated \$2,000,000 for each of the fiscal years
24 1998 through 2001.”.

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