

105TH CONGRESS
1ST SESSION

S. 419

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

IN THE SENATE OF THE UNITED STATES

MARCH 11, 1997

Mr. BOND (for himself, Mr. LOTT, Mr. HOLLINGS, Mr. HUTCHINSON, Mr. COCHRAN, Mr. KOHL, Mr. INOUE, Mr. MOYNIHAN, Mr. CHAFEE, Mr. DASCHLE, Mr. BREAUX, Mr. HELMS, Mr. WYDEN, Mr. KERREY, Mr. FAIRCLOTH, Ms. MOSELEY-BRAUN, Mr. BINGAMAN, and Mr. DORGAN) introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

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:

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

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

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

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

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

3 Part B of title III of the Public Health Service Act
4 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
5 tion 317F the following:

6 “BIRTH DEFECTS PREVENTION AND RESEARCH
7 PROGRAMS

8 “SEC. 317G. (a) NATIONAL BIRTH DEFECTS SUR-
9 VEILLANCE PROGRAM.—The Secretary, acting through
10 the Director of the Centers for Disease Control, may
11 award grants to, enter into cooperative agreements with,
12 or provide direct technical assistance in lieu of cash to
13 States, State health authorities, or health agencies of po-
14 litical subdivisions of a State for collection, analysis, and
15 reporting of birth defects statistics from birth certificates,
16 infant death certificates, hospital records, or other sources
17 and to collect and disaggregate such statistics by gender
18 and racial and ethnic group.

19 “(b) CENTERS OF BIRTH DEFECTS PREVENTION RE-
20 SEARCH.—

21 “(1) IN GENERAL.—The Secretary shall estab-
22 lish at least five regional birth defects monitoring
23 and research programs for the purpose of collecting
24 and analyzing information on the number, incidence,
25 correlates, and causes of birth defects, to include in-
26 formation regarding gender and different racial and

1 ethnic groups, including Hispanics, non-Hispanic
2 whites, African Americans, Native Americans, and
3 Asian Americans.

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

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

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

22 “(B) the program will coordinate States
23 birth defects surveillance and prevention efforts
24 within a region;

1 “(C) education, training, and clinical skills
2 improvement for health professionals aimed at
3 the prevention and control of birth defects will
4 be included in the program activities;

5 “(D) development and evaluation of birth
6 defects prevention strategies will be included in
7 the program activities, as appropriate; and

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

10 “(4) CENTERS TO FOCUS ON RACIAL AND ETH-
11 NIC DISPARITIES IN BIRTH DEFECTS.—One of the
12 Centers of Birth Defects Prevention Research shall
13 focus on birth defects among ethnic minorities, and
14 shall be located in a standard metropolitan statis-
15 tical area that has over a 60 percent ethnic minority
16 population, is federally designated as a health pro-
17 fessional shortage area, and has an incidence of one
18 or more birth defects more than four times the na-
19 tional average.

20 “(c) CLEARINGHOUSE.—The Centers for Disease
21 Control shall serve as the coordinating agency for birth
22 defects prevention activities through establishment of a
23 clearinghouse for the collection and storage of data and
24 generated from birth defects monitoring programs devel-
25 oped under subsections (a) and (b). Functions of such

1 clearinghouse shall include facilitating the coordination of
2 research and policy development to prevent birth defects.
3 The clearinghouse shall disaggregate data by gender and
4 by racial and ethnic groups, the major Hispanic sub-
5 groups, non-Hispanic whites, African Americans, Native
6 Americans, and Asian Americans.

7 “(d) PREVENTION STRATEGIES.—

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

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

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

1 “(ii) at least one outcome research
2 project to study the effectiveness of infant
3 interventions aimed at amelioration of
4 birth defects; and

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

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

22 “(e) ADVISORY COMMITTEE.—

23 “(1) ESTABLISHMENT OF COMMITTEE.—The
24 Secretary shall establish an Advisory Committee for
25 Birth Defects Prevention (in this subsection referred

1 to as the ‘Committee’). The Committee shall provide
2 advice and recommendations on prevention and ame-
3 lioration of birth defects to the Secretary and the
4 Director of the Centers for Disease Control.

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

7 “(A) make recommendations regarding
8 prevention research and intervention priorities;

9 “(B) study and recommend ways to pre-
10 vent birth defects, with emphasis on emerging
11 technologies;

12 “(C) identify annually the important areas
13 of government and nongovernment cooperation
14 needed to implement prevention strategies;

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

21 “(E) review and recommend policies and
22 guidance related to birth defects research and
23 prevention.

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

4 “(A) four health professionals, who are not
5 employees of the United States, who have ex-
6 pertise in issues related to prevention of or care
7 for children with birth defects;

8 “(B) two representatives from health pro-
9 fessional associations;

10 “(C) four representatives from voluntary
11 health agencies concerned with conditions lead-
12 ing to birth defects or childhood disability;

13 “(D) five members of the general public, of
14 whom at least three shall be parents of children
15 with birth defects or persons having birth de-
16 fects; and

17 “(E) representatives of the Public Health
18 Service agencies involved in birth defects re-
19 search and prevention programs and represent-
20 atives of other appropriate Federal agencies, in-
21 cluding but not limited to the Department of
22 Education and the Environmental Protection
23 Agency, shall be appointed as ex officio, liaison

1 members for purposes of informing the Com-
2 mittee regarding Federal agency policies and
3 practices;

4 “(4) STRUCTURE.—

5 “(A) TERM OF OFFICE.—Appointed mem-
6 bers of the Committee shall be appointed for a
7 term of office of 3 years, except that of the
8 members first appointed, 5 shall be appointed
9 for a term of 1 year, 5 shall be appointed for
10 a term of 2 years, and 5 shall be appointed for
11 a term of 3 years, as determined by the Sec-
12 retary.

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

16 “(C) COMPENSATION.—Members of the
17 Committee who are employees of the Federal
18 Government shall serve without compensation.
19 Members of the Committee who are not employ-
20 ees of the Federal Government shall be com-
21 pensated at a rate not to exceed the daily equiv-
22 alent of the rate in effect for grade GS–18.

1 “(f) REPORT.—The Secretary shall prepare and sub-
2 mit to the Committee on Commerce of the House of Rep-
3 resentatives and the Committee on Labor and Human Re-
4 sources of the Senate a biennial report regarding the inci-
5 dence of birth defects, the contribution of birth defects to
6 infant mortality, the outcome of implementation of preven-
7 tion strategies, and identified needs for research and pol-
8 icy development to include information regarding the var-
9 ious racial and ethnic groups, including Hispanic, non-
10 Hispanic whites, African Americans, Native Americans,
11 and Asian Americans.

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

18 “(h) AUTHORIZATION OF APPROPRIATIONS.—

19 “(1) For the purpose of carrying out sub-
20 sections (a), (b), and (c), there are authorized to be
21 appropriated \$15,000,000 for fiscal year 1998,
22 \$20,000,000 for fiscal year 1999, and such sums as
23 may be necessary for each of the fiscal years 2000
24 and 2001.

1 “(2) For the purpose of carrying out subsection
2 (d), there are authorized to be appropriated
3 \$15,000,000 for fiscal year 1998, \$20,000,000 for
4 fiscal year 1999, and such sums as may be nec-
5 essary for each of the fiscal years 2000 and 2001.

6 “(3) For the purpose of carrying out sub-
7 sections (e) and (f), there are authorized to be ap-
8 propriated \$2,000,000 for each of the fiscal years
9 1998 through 2001.”.

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