

108TH CONGRESS
1ST SESSION

S. 1726

To reduce preterm labor and delivery and the risk of pregnancy-related deaths and complications due to pregnancy, and to reduce infant mortality caused by prematurity.

IN THE SENATE OF THE UNITED STATES

OCTOBER 14, 2003

Mr. ALEXANDER (for himself and Mr. DODD) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To reduce preterm labor and delivery and the risk of pregnancy-related deaths and complications due to pregnancy, and to reduce infant mortality caused by prematurity.

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.**

4 This Act may be cited as the “Prematurity Research
5 Expansion and Education for Mothers who deliver Infants
6 Early Act” or the “PREEMIE Act”.

7 **SEC. 2. FINDINGS AND PURPOSE.**

8 (a) FINDINGS.—Congress makes the following find-
9 ings:

1 (1) Premature birth is a serious and growing
2 problem. The rate of preterm birth increased 27 per-
3 cent between 1981 and 2001 (from 9.4 percent to
4 11.9 percent). In 2001, more than 476,000 babies
5 were born prematurely in the United States.

6 (2) Preterm birth accounts for 23 percent of
7 deaths in the first month of life.

8 (3) Premature infants are 14 times more likely
9 to die in the first year of life.

10 (4) Premature babies who survive may suffer
11 lifelong consequences, including cerebral palsy, men-
12 tal retardation, chronic lung disease, and vision and
13 hearing loss.

14 (5) Preterm and low birthweight birth is a sig-
15 nificant financial burden in health care. The esti-
16 mated charges for hospital stays for infants with any
17 diagnosis of prematurity/low birthweight were
18 \$11,900,000,000 in 2000. The average lifetime med-
19 ical costs of a premature baby are conservatively es-
20 timated at \$500,000.

21 (6) The proportion of preterm infants born to
22 African-American mothers (17.3 percent) was sig-
23 nificantly higher compared to the rate of infants
24 born to white mothers (10.6 percent). Prematurity

1 or low birthweight is the leading cause of death for
2 African-American infants.

3 (7) The cause of approximately half of all pre-
4 mature births is unknown.

5 (8) Women who smoke during pregnancy are
6 twice as likely as nonsmokers to give birth to a low
7 birthweight baby. Babies born to smokers weigh, on
8 average, 200 grams less than nonsmokers' babies.

9 (9) To reduce the rates of preterm labor and
10 delivery more research is needed on the underlying
11 causes of preterm delivery, the development of treat-
12 ments for prevention of preterm birth, and treat-
13 ments improving outcomes for infants born preterm.

14 (b) PURPOSES.—It the purpose of this Act to—

15 (1) reduce rates of preterm labor and delivery;

16 (2) work toward an evidence-based standard of
17 care for pregnant women at risk of preterm labor or
18 other serious complications, and for infants born
19 preterm and at a low birthweight; and

20 (3) reduce infant mortality and disabilities
21 caused by prematurity.

1 **SEC. 3. RESEARCH RELATING TO PRETERM LABOR AND DE-**
2 **LIVERY AND THE CARE, TREATMENT, AND**
3 **OUTCOMES OF PRETERM AND LOW BIRTH-**
4 **WEIGHT INFANTS.**

5 (a) GENERAL EXPANSION OF NIH RESEARCH.—
6 Part B of title IV of the Public Health Service Act (42
7 U.S.C. 284 et seq.) is amended by adding at the end the
8 following:

9 **“SEC. 409J. EXPANSION AND COORDINATION OF RESEARCH**
10 **RELATING TO PRETERM LABOR AND DELIV-**
11 **ERY AND INFANT MORTALITY.**

12 “(a) IN GENERAL.—The Director of NIH shall ex-
13 pand, intensify, and coordinate the activities of the Na-
14 tional Institutes of Health with respect to research on the
15 causes of preterm labor and delivery, infant mortality, and
16 improving the care and treatment of preterm and low
17 birthweight infants.

18 “(b) AUTHORIZATION OF RESEARCH NETWORKS.—
19 There shall be established within the National Institutes
20 of Health a Maternal-Fetal Medicine Units Network and
21 a Neonatal Research Units Network. In complying with
22 this subsection, the Director of NIH shall utilize existing
23 networks.

24 “(c) AUTHORIZATION OF APPROPRIATIONS.—There
25 are authorized to be appropriated to carry out this section,

1 such sums as may be necessary for each of fiscal years
2 2004 through 2008.”.

3 (b) GENERAL EXPANSION OF CDC RESEARCH.—
4 Section 301 of the Public Health Service Act (42 U.S.C.
5 241 et seq.) is amended by adding at the end the fol-
6 lowing:

7 “(e) The Director of the Centers for Disease Control
8 and Prevention shall expand, intensify, and coordinate the
9 activities of the Centers for Disease Control and Preven-
10 tion with respect to preterm labor and delivery and infant
11 mortality.”.

12 (c) STUDY ON ASSISTED REPRODUCTION TECH-
13 NOLOGIES.—Section 1004(c) of the Children’s Health Act
14 of 2000 (Public Law 106–310) is amended—

15 (1) in paragraph (2), by striking “and” at the
16 end;

17 (2) in paragraph (3), by striking the period and
18 inserting “; and”; and

19 (3) by adding at the end the following:

20 “(4) consider the impact of assisted reproduc-
21 tion technologies on the mother’s and children’s
22 health and development.”.

23 (d) STUDY ON RELATIONSHIP BETWEEN PRE-
24 MATURITY AND BIRTH DEFECTS.—

1 (1) IN GENERAL.—The Director of the Centers
2 for Disease Control and Prevention shall conduct a
3 study on the relationship between prematurity, birth
4 defects, and developmental disabilities.

5 (2) REPORT.—Not later than 2 year after the
6 date of enactment of this Act, the Director of the
7 Centers for Disease Control and Prevention shall
8 submit to the appropriate committees of Congress a
9 report concerning the results of the study conducted
10 under paragraph (1).

11 (e) REVIEW OF PREGNANCY RISK ASSESSMENT
12 MONITORING SURVEY.—The Director of the Centers for
13 Disease Control and Prevention shall conduct a review of
14 the Pregnancy Risk Assessment Monitoring Survey to en-
15 sure that the Survey includes information relative to med-
16 ical care and intervention received, in order to track preg-
17 nancy outcomes and reduce instances of preterm birth.

18 (f) STUDY ON THE HEALTH AND ECONOMIC CON-
19 SEQUENCES OF PRETERM BIRTH.—

20 (1) IN GENERAL.—The Director of the National
21 Institutes of Health in conjunction with the Director
22 of the Centers for Disease Control and Prevention
23 shall enter into a contract with the Institute of Med-
24 icine of the National Academy of Sciences for the
25 conduct of a study to define and address the health

1 and economic consequences of preterm birth. In con-
2 ducting the study, the Institute of Medicine shall—

3 (A) review and assess the epidemiology of
4 premature birth and low birthweight, and the
5 associated maternal and child health effects in
6 the United States, with attention paid to cat-
7 egories of gestational age, plurality, maternal
8 age, and racial or ethnic disparities;

9 (B) review and describe the spectrum of
10 short and long-term disability and health-re-
11 lated quality of life associated with premature
12 births and the impact on maternal health,
13 health care and quality of life, family employ-
14 ment, caregiver issues, and other social and fi-
15 nancial burdens;

16 (C) assess the direct and indirect costs as-
17 sociated with premature birth, including mor-
18 bidity, disability, and mortality;

19 (D) identify gaps and provide rec-
20 ommendations for feasible systems of moni-
21 toring and assessing associated economic and
22 quality of life burdens associated with pre-
23 maturity;

24 (E) explore the implications of the burden
25 of premature births for national health policy;

1 (F) identify community outreach models
2 that are effective in decreasing prematurity
3 rates in communities;

4 (G) consider options for addressing, as ap-
5 propriate, the allocation of public funds to bio-
6 medical and behavioral research, the costs and
7 benefits of preventive interventions, public
8 health, and access to health care; and

9 (H) provide recommendations on best
10 practices and interventions to prevent pre-
11 mature birth, as well as the most promising
12 areas of research to further prevention efforts.

13 (2) REPORT.—Not later than 1 year after the
14 date on which the contract is entered into under
15 paragraph (1), the Institute of Medicine shall submit
16 to the Director of the National Institutes of Health,
17 the Director of the Centers for Disease Control and
18 Prevention, and the appropriate committees of Con-
19 gress a report concerning the results of the study
20 conducted under such paragraph.

21 (g) EVALUATION OF NATIONAL CORE PERFORMANCE
22 MEASURES.—

23 (1) IN GENERAL.—The Administrator of the
24 Health Resources and Services Administration shall
25 conduct an assessment of the current national core

1 performance measures and national core outcome
 2 measures utilized under the Maternal and Child
 3 Health Block Grant under title V of the Social Secu-
 4 rity Act (42 U.S.C. 701 et seq.) for purposes of ex-
 5 panding such measures to include some of the
 6 known risk factors of low birthweight and pre-
 7 maturity, including the percentage of infants born to
 8 pregnant women who smoked during pregnancy.

9 (2) REPORT.—Not later than 1 year after the
 10 date of enactment of this Act, the Administrator of
 11 the Health Resources and Services Administration
 12 shall submit to the appropriate committees of Con-
 13 gress a report concerning the results of the evalua-
 14 tion conducted under paragraph (1).

15 **SEC. 4. PUBLIC AND HEALTH CARE PROVIDER EDUCATION**
 16 **AND SUPPORT SERVICES.**

17 Part P of title III of the Public Health Service Act
 18 (42 U.S.C. 280g et seq.) is amended by adding at the end
 19 the following:

20 **“SEC. 3990. PUBLIC AND HEALTH CARE PROVIDER EDU-**
 21 **CATION AND SUPPORT SERVICES.**

22 “(a) IN GENERAL.—The Secretary, directly or
 23 through the awarding of grants to public or private non-
 24 profit entities, shall conduct a demonstration project to
 25 improve the provision of information on prematurity to

1 health professionals and other health care providers and
2 the public.

3 “(b) ACTIVITIES.—Activities to be carried out under
4 the demonstration project under subsection (a) shall in-
5 clude the establishment of programs—

6 “(1) to provide information and education to
7 health professionals, other health care providers, and
8 the public concerning—

9 “(A) the signs of preterm labor, updated
10 as new research results become available;

11 “(B) the screening for and the treating of
12 infections;

13 “(C) counseling on optimal weight and
14 good nutrition, including folic acid;

15 “(D) smoking cessation education and
16 counseling; and

17 “(E) stress management; and

18 “(2) to improve the treatment and outcomes for
19 babies born premature, including the use of evi-
20 dence-based standards of care by health care profes-
21 sionals for pregnant women at risk of preterm labor
22 or other serious complications and for infants born
23 preterm and at a low birthweight.

24 “(c) REQUIREMENT.—Any program or activity fund-
25 ed under this section shall be evidence-based.

1 “(d) NICU FAMILY SUPPORT PROGRAMS.—The Sec-
2 retary shall conduct, through the awarding of grants to
3 public and nonprofit private entities, projects to respond
4 to the emotional and informational needs of families dur-
5 ing the stay of an infant in a neonatal intensive care unit,
6 during the transition of the infant to the home, and in
7 the event of a newborn death. Activities under such
8 projects may include providing books and videos to fami-
9 lies that provide information about the neonatal intensive
10 care unit experience, and providing direct services that
11 provide emotional support within the neonatal intensive
12 care unit setting.

13 “(e) 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 fiscal years
16 2004 through 2008.”.

17 **SEC. 5. INTERAGENCY COORDINATING COUNCIL ON PRE-**
18 **MATURITY AND LOW BIRTHWEIGHT.**

19 (a) PURPOSE.—It is the purpose of this section to
20 stimulate multidisciplinary research, scientific exchange,
21 and collaboration among the agencies of the Department
22 of Health and Human Services and to assist the Depart-
23 ment in targeting efforts to achieve the greatest advances
24 toward the goal of reducing prematurity and low birth-
25 weight.

1 (b) ESTABLISHMENT.—The Secretary of Health and
2 Human Services shall establish an Interagency Coordi-
3 nating Council on Prematurity and Low Birthweight (re-
4 ferred to in this section as the Council) to carry out the
5 purpose of this section.

6 (c) COMPOSITION.—The Council shall be composed of
7 members to be appointed by the Secretary, including rep-
8 resentatives of—

9 (1) the agencies of the Department of Health
10 and Human Services; and

11 (2) voluntary health care organizations, includ-
12 ing grassroots advocacy organizations, providers of
13 specialty obstetrical and pediatric care, and re-
14 searcher organizations.

15 (d) ACTIVITIES.—The Council shall—

16 (1) annually report to the Secretary of Health
17 and Human Services on current Departmental ac-
18 tivities relating to prematurity and low birthweight;

19 (2) plan and hold a conference on prematurity
20 and low birthweight under the sponsorship of the
21 Surgeon General;

22 (3) establish a consensus research plan for the
23 Department of Health and Human Services on pre-
24 maturity and low birthweight;

1 (4) report to the Secretary of Health and
2 Human Services and the appropriate committees of
3 Congress on recommendations derived from the con-
4 ference held under paragraph (2) and on the status
5 of Departmental research activities concerning pre-
6 maturity and low birthweight;

7 (5) carry out other activities determined appro-
8 priate by the Secretary of Health and Human Serv-
9 ices; and

10 (6) oversee the coordination of the implementa-
11 tion of this Act.

12 **SEC. 6. AUTHORIZATION OF APPROPRIATIONS.**

13 There are authorized to be appropriated to carry out
14 this Act, such sums as may be necessary for each of fiscal
15 years 2004 through 2008.

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