

105TH CONGRESS
1ST SESSION

H. R. 1788

To amend the Public Health Service Act to ensure adequate research and education regarding the drug DES.

IN THE HOUSE OF REPRESENTATIVES

JUNE 4, 1997

Ms. SLAUGHTER (for herself, Mrs. MINK of Hawaii, Ms. CHRISTIAN-GREEN, Mr. LAFALCE, Mr. KANJORSKI, Mrs. MALONEY of New York, Mrs. MORELLA, Mr. NADLER, Ms. NORTON, Ms. PELOSI, Mr. STARK, Mr. TOWNS, Ms. WATERS, Mr. WAXMAN, and Ms. WOOLSEY) introduced the following bill; which was referred to the Committee on Commerce

A BILL

To amend the Public Health Service Act to ensure adequate research and education regarding the drug DES.

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 “DES Education and
5 Research Amendments of 1997”.

6 **SEC. 2. FINDINGS.**

7 With respect to diethylstilbestrol (a drug commonly
8 known as DES), the Congress finds as follows:

1 (1) DES was widely prescribed to American
2 women from 1938 to 1971 in the mistaken belief it
3 would prevent miscarriage. Approximately 5,000,000
4 pregnant women took the drug, resulting in DES ex-
5 posure for approximately 5,000,000 daughters and
6 sons.

7 (2) Studies conducted since the 1970s have
8 shown that DES damages the reproductive systems
9 of those exposed in utero and increases the risk for
10 cancer, infertility, and a wide range of other serious
11 reproductive tract disorders. These disorders include
12 a five-fold increased risk for ectopic pregnancy for
13 DES daughters and a three-fold increase in risk for
14 miscarriage and preterm labor. Studies have indi-
15 cated that exposure to DES may increase the risk
16 for autoimmune disorders and diseases.

17 (3) An estimated 1 in 1,000 women exposed to
18 DES in utero will develop clear cell cancer of the va-
19 gina or cervix. While survival rates for clear cell can-
20 cer are over 80 percent when it is detected early,
21 there is still no effective treatment for recurrences of
22 this cancer.

23 (4) Studies also indicate a higher incidence of
24 breast cancer among mothers who took DES during
25 pregnancy.

1 (5) While research on DES and its effects has
2 produced important advances to date, much more re-
3 mains to be learned.

4 (6) Two of the most pressing research concerns
5 at present are whether estrogen replacement therapy
6 is advisable for DES-exposed women and whether
7 DES may have a genetic impact on the third genera-
8 tion—the children of parents exposed to DES in
9 utero.

10 (7) All DES-exposed individuals have special
11 screening and health care needs, especially during
12 annual gynecological examinations and pregnancy
13 for DES daughters, who should receive high risk
14 care.

15 (8) Many Americans remain unaware of their
16 DES exposure or ignorant about proper health care
17 and screening. There remains a great need for a na-
18 tional education effort to inform both the public and
19 health care providers about the health effects and
20 proper health care practices for DES-exposed indi-
21 viduals.

1 **SEC. 3. REVISION AND EXTENSION OF PROGRAM FOR RE-**
2 **SEARCH AND AUTHORIZATION OF NEW NA-**
3 **TIONAL PROGRAM OF EDUCATION REGARD-**
4 **ING DRUG DES.**

5 (a) PERMANENT EXTENSION OF GENERAL PRO-
6 GRAM.—Section 403A(e) of the Public Health Service Act
7 (42 U.S.C. 283a(e)) is amended by striking “for each of
8 the fiscal years 1993 through 1996” and inserting “for
9 fiscal year 1997 and each subsequent fiscal year”.

10 (b) NATIONAL PROGRAM FOR EDUCATION OF
11 HEALTH PROFESSIONALS AND PUBLIC.—From amounts
12 appropriated for carrying out section 403A of the Public
13 Health Service Act, the Secretary of Health and Human
14 Services, acting through the heads of the appropriate
15 agencies of the Public Health Service, shall carry out a
16 national program for the education of health professionals
17 and the public with respect to the drug diethylstilbestrol
18 (commonly know as DES). To the extent appropriate,
19 such national program shall use methodologies developed
20 through the education demonstration program carried out
21 under such section 403A. In developing and carrying out
22 the national program, the Secretary shall consult closely
23 with representatives of nonprofit private entities that rep-
24 resent individuals who have been exposed to DES and that
25 have expertise in community-based information campaigns
26 for the public and for health care providers. The imple-

1 mentation of the national program shall begin during fis-
2 cal year 1998.

○