

105TH CONGRESS  
1ST SESSION

# H. R. 1788

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

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## 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

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## 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.

