105TH CONGRESS 1ST SESSION

S. 834

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

IN THE SENATE OF THE UNITED STATES

June 5, 1997

Mr. Harkin (for himself and Mr. Reed) introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

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 Research and
- 5 Education Amendments of 1997".
- 6 SEC. 2. FINDINGS.
- With respect to diethylstilbestrol (a drug commonly
- 8 known as DES), the Congress finds as follows:
- 9 (1) DES was widely prescribed to American
- women from 1938 to 1971 in the mistaken belief it

- would prevent miscarriage. Approximately 5,000,000 pregnant women took the drug, resulting in DES exposure for approximately 5,000,000 daughters and sons.
 - (2) Studies conducted since the 1970s have shown that DES damages the reproductive systems of those exposed in utero and increases the risk for cancer, infertility, and a wide range of other serious reproductive tract disorders. These disorders include a five-fold increased risk for ectopic pregnancy for DES daughters and a three-fold increase in risk for miscarriage and preterm labor. Studies have indicated that exposure to DES may increase the risk for autoimmune disorders and diseases.
 - (3) An estimated 1 in 1,000 women exposed to DES in utero will develop clear cell cancer of the vagina or cervix. While survival rates for clear cell cancer are over 80 percent when it is detected early, there is still no effective treatment for recurrences of this cancer.
 - (4) Studies also indicate a higher incidence of breast cancer among mothers who took DES during 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.
 - (6) Preliminary research results indicate that DES exposure may have a genetic impact on the third generation—the children of parents exposed to DES in utero—and that estrogen replacement therapy may not be advisable for DES-exposed women.
 - (7) All DES-exposed individuals have special screening and health care needs, especially during gynecological exams and pregnancy for DES daughters, who should receive high risk care.
- 13 (8) Many Americans remain unaware of their
 14 DES exposure or ignorant about proper health care
 15 and screening. There remains a great need for a na16 tional education effort to inform both the public and
 17 health care providers about the health effects and
 18 proper health care practices for DES-exposed indi19 viduals.
- 20 SEC. 3. REVISION AND EXTENSION OF PROGRAM FOR RE-
- 21 SEARCH AND AUTHORIZATION OF NEW NA-
- 22 TIONAL PROGRAM OF EDUCATION REGARD-
- 23 ING DRUG DES.
- 24 (a) PERMANENT EXTENSION OF GENERAL PRO-25 GRAM.—Section 403A(e) of the Public Health Service Act

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- 1 (42 U.S.C. 283a(e)) is amended by striking "for each of
- 2 the fiscal years 1993 through 1996" and inserting "for
- 3 fiscal year 1997 and each subsequent fiscal year".
- 4 (b) National Program for Education of
- 5 HEALTH PROFESSIONALS AND PUBLIC.—From amounts
- 6 appropriated for carrying out section 403A of the Public
- 7 Health Service Act (42 U.S.C. 283a), the Secretary of
- 8 Health and Human Services, acting through the heads of
- 9 the appropriate agencies of the Public Health Service,
- 10 shall carry out a national program for the education of
- 11 health professionals and the public with respect to the
- 12 drug diethylstilbestrol (commonly know as DES). To the
- 13 extent appropriate, such national program shall use meth-
- 14 odologies developed through the education demonstration
- 15 program carried out under such section 403A. In develop-
- 16 ing and carrying out the national program, the Secretary
- 17 shall consult closely with representatives of nonprofit pri-
- 18 vate entities that represent individuals who have been ex-
- 19 posed to DES and that have expertise in community-based
- 20 information campaigns for the public and for health care
- 21 providers. The implementation of the national program
- 22 shall begin during fiscal year 1998.

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