

CDC's *DES Update* Fact Sheet

For the past 30 years, researchers have been monitoring the health risks experienced by people exposed to diethylstilbestrol (DES). Through these efforts, researchers have identified related health risks and have answered many questions about the effects of DES exposure.

However, many questions about the long-term health risks of DES exposure remain unanswered. CDC's *DES Update* will provide research updates about confirmed health risks and potential health problems that have not been identified or confirmed at this point.

Who Is at Risk

In the United States, an estimated 5–10 million people were exposed to DES:

- **Women who were pregnant during 1938—1971 and who were prescribed DES** to prevent miscarriages or premature deliveries.
- **DES Daughters**, women who were exposed to DES in the womb
- **DES Sons**, men who were exposed to DES in the womb

Known DES Health Risks

Research available through CDC's *DES Update* currently confirms the following health risks associated with DES exposure:

- **Women who were prescribed DES while pregnant** are at a modestly increased risk for breast cancer. Studies have shown a 30percent higher risk for breast cancer among women prescribed DES while pregnant than among women who were not prescribed DES.
- **DES Daughters** are at an increased risk for clear-cell adenocarcinoma (CCA), a rare vaginal and cervical cancer; reproductive tract structural differences; pregnancy complications, such as ectopic (tubal) pregnancies and preterm deliveries; and infertility.
 - CCA has been diagnosed in DES Daughters up to age 50.
 - DES Daughters are 40 times more likely to develop CCA of the vagina and cervix than unexposed women.
 - Studies have shown that up to a third of DES Daughters were born with or developed some form of reproductive tract abnormality of the cervix, uterus, or Fallopian tubes.
- **DES Sons** have a lifelong, increased risk for noncancerous epididymal cysts (growths on testicles). However, it remains unclear whether DES exposure increases the risk for other genital abnormalities or testicular cancer in men.

Additional Research on Health Risks

Breast Cancer

- Early detection of breast cancer is the best course of action for women who were prescribed DES while pregnant. To increase chances for early breast cancer detection, CDC's *DES Update* encourages women to follow a regular schedule for breast cancer screening recommended by their health care providers.
- Providers may recommend practicing breast self-examinations as a way to detect any lumps in the breasts and scheduling mammogram examinations every one to two years for women 40 years of age or older.
- In a 2002 study published in *Cancer Causes and Control*, DES Daughters older than 40 years of age were 2.5 times more likely to experience breast cancer than were unexposed women older than 40 years of age. Findings of the study are not definitive, but they suggest that exposure to DES in the womb may also be associated with an increased risk of breast cancer.

Clear-Cell Adenocarcinoma (CCA)

- Approximately one of every 1,000 DES Daughters will develop CCA of the vagina or the cervix.
- Most cases of CCA of the vagina and cervix have occurred in women in their late teens and early 20s. However, a small number of DES-related clear-cell cancers have been diagnosed in women in their 30s and 40s. Because CCA is a continued health risk, DES Daughters should be screened for CCA throughout their lifetimes.

Reproductive Complications and Infertility

- Of DES Daughters, 64 percent carried their first pregnancy to term, compared with 85 percent of unexposed women. Approximately 20 percent of DES Daughters experience preterm labor, compared with 8 percent of unexposed women.
- Estimates of a DES Daughter's risk for an ectopic (tubal) pregnancy range from three to five times higher than the risk of an unexposed woman.
- According to a 2000 study published in *Obstetrics & Gynecology*, 20 percent of DES Daughters had a miscarriage during their first pregnancy, compared with approximately 10 percent of unexposed women.
- According to a 2001 infertility study published in the *American Journal of Epidemiology*, 24 percent of DES Daughters were unable to become pregnant, compared with 18 percent of unexposed women. Additionally, 28 percent of DES Daughters had tried for 12 months to become pregnant without success, compared with 16 percent of unexposed women.

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Genital Abnormalities in Men

- DES Sons have an increased risk of noncancerous epididymal cysts. A 1979 study published in the *Journal of Urology* found that 21 percent of DES Sons had epididymal cysts compared with 5 percent of unexposed men.
- A few studies have reported that DES Sons experience a greater likelihood of being born with other genital abnormalities. Although estimates vary, one 1995 study published in *Obstetrical & Gynecological Survey* identified that DES Sons have a 15 percent chance of genital abnormalities, compared with 5 percent of unexposed men. Because findings have been inconsistent, researchers cannot say with certainty that DES causes genital abnormalities in DES Sons.

Assessing the Likelihood of DES Exposure

- CDC's *DES Update* Web site includes the *DES Update Self-Assessment Guide* which features a series of questions designed to help individuals assess their likelihood of DES exposure.
- In the United States, those people who may have been exposed to DES include women who were pregnant and individuals who were born during 1938—1971.
- An interactive version of CDC's *DES Update Self-Assessment Guide* is free and available online at www.cdc.gov/DES. Individuals can also request a printed version by calling tollfree at 1-888-232-6789.

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