

CDC's DES Update Backgrounder

About Diethylstilbestrol (DES)

History

Diethylstilbestrol (DES) is a synthetic estrogen that physicians prescribed to pregnant women during 1938–1971 to prevent miscarriages or premature delivery. In the United States, an estimated 5–10 million people were exposed to DES, including women who were prescribed DES while pregnant and their children born during this time. The following timeline provides an overview of key dates and milestones throughout the history of DES.

- (1938) DES Introduced DES was first developed, and doctors began prescribing the drug to
 pregnant woman who experienced miscarriages or premature deliveries. DES was originally
 considered effective and safe for both pregnant women and their developing babies.
- (1953) DES Challenged Published research in the American Journal of Obstetrics and Gynecology
 indicated that DES did not prevent miscarriages or premature births. However, physicians continued
 to prescribe DES to pregnant women until 1971.
- (1971) DES Warning Issued Another study published in the *New England Journal of Medicine* identified DES as a cause of clear-cell adenocarcinoma (CCA), a rare vaginal cancer in girls and young women who had been exposed to DES in the womb. On the basis of this study, the Food and Drug Administration (FDA) issued a *Drug Bulletin* advising physicians to stop prescribing DES to pregnant women.
- (1978) DES Task Force Recommends Notification The National DES Task Force issued a physician advisory recommending that all physicians review their medical records and notify women who were prescribed DES while pregnant.
- (1971–2002) DES Health Risks Revealed Additional research linked DES exposure to health risks
 among the women who were prescribed DES while pregnant and to the children born of these
 pregnancies. Women who were prescribed DES while pregnant are at a modestly increased risk for
 breast cancer. Women exposed to DES in the womb—DES Daughters—have a lifelong, increased
 risk for CCA, for reproductive complications, and for infertility. Men exposed to DES—DES Sons—
 are at an increased risk for noncancerous epididymal cysts (growths on the testicles).
- (2003) CDC's DES Update Campaign Begins CDC spearheads a national campaign to update consumers and health care providers about DES.

ABOUT CDC'S DES UPDATE

Overview

CDC's *DES Update* was developed to provide the public and health care providers with the most current and accurate information about DES. CDC's *DES Update* combines more than 30 years of research on the effects of DES exposure. The *Update* includes resources to help people learn about related health risks and find current research related to DES exposure. The *Update* also includes a brochure to help people assess their likelihood of DES exposure. This national effort is funded by Congress and was developed in partnership with the National Cancer Institute and several other organizations.

Objectives

The main goal of CDC's *DES Update* is to provide a comprehensive resource for individuals who may have been exposed to DES. This program provides a single resource that contains the most comprehensive information about DES, including findings from continuing studies on the health effects of DES exposure.

CDC's DES Update helps individuals do the following:

- Learn more about how exposure to DES could affect them, their family, and their friends
- Access materials to share with health care providers and to initiate conversations about potential DES exposure
- Share information about DES with others
- Assess their personal likelihood of DES exposure
- Stay up-to-date on research about the effects of exposure to DES

Materials and Resources

CDC's *DES Update* Web site provides free resources and materials for consumers and health care providers, including the following:

- **Downloadable DES Update fact sheets and research** about known health risks associated with DES exposure.
- CDC's DES Update Self-Assessment Guide and other resources for individuals unsure of their DES exposure to help them assess their personal likelihood of exposure and to help them learn what steps they can take. Individuals can access an online, interactive version of the guide and then download and print free copies for themselves, or they can call a toll-free phone number to request their own copies.
- Downloadable educational materials for health care providers including DES case studies, presentations, and self-study materials.

These materials are available by visiting CDC's *DES Update* Web site (<u>www.cdc.gov/DES</u>), or by calling CDC's *DES Update* tollfree phone number at **1-888-232-6789**.

CDC's DES Update Partners

CDC has been working with advocacy and health care provider partners around the country to research, develop, and distribute information about DES. Following is a list of partners:

American Academy of Physician Assistants National Association of Nurse Practitioners in Women's

American College of Nurse-Midwives

Health

American College of Obstetricians and Gynecologists

National Cancer Institute, National Institutes of Health

American Medical Association National Centers of Excellence in Women's Health

American Medical Women's Association National Women's Health Network

American Nurses Association

Office on Women's Health, Department of Health and Human Services

Association of Reproductive Health Professionals

Registry for De

Registry for Research on Hormonal Transpacental

DES Action USA Carcinogenesis, University of Chicago

DES Cancer Network RESOLVE: The National Infertility Association

DES Sons Network

Y-ME Indianapolis

Mennonite College of Nursing at Illinois State University

Y-ME Chattanooga

The Centers for Disease Control and Prevention (CDC) protects people's health and safety by preventing and controlling diseases and injuries; enhances health decisions by providing credible information on critical health issues; and promotes healthy living through strong partnerships with local, national, and international organizations.