

CDC'S DES UPDATE

Overview

The Centers for Disease Control and Prevention (CDC) have developed CDC's DES Update so the public and health care providers have the latest, most comprehensive, and accurate information about diethylstilbestrol (DES).

CDC's DES Update was funded by the U.S. Congress and developed in conjunction with the National Cancer Institute (NCI) and many partner organizations. Researchers have been studying the effects of DES exposure for more than 30 years. However, not all persons who were exposed to DES nor their health care providers have always known the latest information about DES.

A key goal of CDC's DES Update is to provide the most comprehensive information about DES, including findings from continuing studies on the health effects of DES exposure. CDC has also designed and distributed DES Update educational materials that give health care providers the latest research and tools they can use to learn more about DES. Ultimately, we want to help patients and health care providers have good discussions about DES and make the right choices to protect patients' health.



CDC'S DES UPDATE

How Can CDC's DES Update Help Me?

CDC's DES Update includes information for persons who want to

- assess whether they might have been exposed to DES;
- know more about how exposure to DES could affect them, their family, and friends;
- stay up-to-date on research about the effects of exposure to DES;
- get advice about talking with health care providers about DES;
- share information about DES with others; and
- contact the DES Update's partner organizations.

CDC's DES Update is a resource for you, your family, and your health care provider. CDC's DES Update includes a Web site (www.cdc.gov/DES) from which you can print and download information, and a toll-free number (1-888-232-6789) that you can call for free printed materials.

CDC's DES Update can help persons who think they may have been exposed to DES. To assess whether you may have been exposed to DES and to learn what you can do about DES exposure, refer to the section of CDC's DES Update titled [DES SELF-ASSESSMENT: A Guide to Understanding Your Risk for DES Exposure](#).

CDC will also sponsor a series of teleconferences, during which researchers and clinicians will present the latest research on DES exposure. The public is invited to call in, and DES researchers and clinicians will be available to answer questions from callers. Summaries of the teleconferences will be posted on CDC's DES Update Web site. For more information about these teleconferences, refer to the section of CDC's DES Update titled [WHAT WE ARE LEARNING ABOUT DES: DES Teleconferences](#).

Is this the first DES educational effort?

CDC's DES Update is the first comprehensive health education program. However, this is not the first effort to reach out to persons who have been affected by DES. In 1971, Dr. Arthur L. Herbst published a study identifying a rare cancer of the vagina, clear cell adenocarcinoma (CCA), as a health risk for females exposed to DES before birth (in the womb). Since then, government agencies and advocacy organizations have been working to inform the public and health care providers about the effects of DES exposure. Following is a timeline of the history of DES:

- **1971:** The Food and Drug Administration (FDA) issued a Drug Bulletin warning physicians that giving DES to a pregnant woman could harm the developing baby in her womb.
- **1972:** Registry of DES Daughters diagnosed with clear cell adenocarcinoma (CCA) was established.
- **1974:** National Cooperative Diethylstilbestrol and Adenosis (DESAD) project began. This project was designed to locate DES Daughters and monitor their health over time.
- **1978:** 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. The Task Force also recommended the initiation of a public health information campaign. In addition, reports about DES appeared in many newspapers, magazines, and television programs.
- **1979:** DES Action USA, a national consumer advocacy group, was started by women who had been prescribed DES while pregnant, and their families.
- **1980:** The research study, DES Mothers, began.
- **1982:** DES Cancer Network, an advocacy and support group for DES Daughters diagnosed with CCA, was formed.
- **1985:** The DES Sons Network was formed in conjunction with DES Action USA.
- **1992:** The National Institutes of Health (NIH) held a national workshop on long-term health effects of exposure to DES. The DES Combined Cohort Study joined five existing study groups to examine the long-term risk for cancer and other adverse effects by studying thousands of people together in one study.
- **1993–1997:** The National Cancer Institute (NCI) conducted regional DES education program pilot studies in five sites, including California, Massachusetts, New York, Texas, and Wisconsin. The results of the pilot studies provided a foundation for CDC's DES Update.
- **1999:** The National Institutes of Health (NIH) held a National DES Research Conference.
- **2003:** CDC launched its national DES Update for consumers and health care providers.

What is CDC's DES Update doing to get the word out?

CDC is working with advocacy and health care provider partners around the country to distribute information about DES. For example, DES advocacy organizations (such as DES Action, DES Cancer Network, and DES Sons Network) are channels to reach people who know they have been exposed to DES. In addition, the National Centers of Excellence in Women's Health developed materials to update health care providers.

The following government and non-government organizations worked with CDC to produce the DES Update:

American Academy of Physician Assistants	National Association of Nurse Practitioners in Women's Health
American College of Nurse-Midwives	National Cancer Institute, National Institutes of Health
American College of Obstetricians and Gynecologists	National Centers of Excellence in Women's Health
American Medical Association	National Women's Health Network
American Medical Women's Association	Office on Women's Health, Department of Health and Human Services
American Nurses Association	Registry for Research on Hormonal Transplacental Carcinogenesis, University of Chicago
Association of Reproductive Health Professionals	RESOLVE: The National Infertility Association
DES Action USA	Y-ME Indianapolis
DES Cancer Network	Y-ME Chattanooga
DES Sons Network	
Mennonite College of Nursing at Illinois State University	