

DES *Self-Assessment*

A Guide to Understanding Your Risk for DES Exposure



1938–1971: DES prescribed for pregnant women
1971–2002: Research identifies long-term DES health risks
2003: CDC's DES UPDATE begins...



What is **DES?**

Diethylstilbestrol (DES) is a synthetic estrogen that was developed to supplement a woman's natural estrogen production. First prescribed by physicians in 1938 for women who experienced miscarriages or premature deliveries, DES was originally considered effective and safe for both the pregnant woman and the developing baby. In the United States, an estimated 5–10 million persons were exposed to DES during 1938–1971, including women who were prescribed DES while pregnant and the female and male children born of these pregnancies. In 1971, the Food and Drug Administration (FDA) issued a Drug Bulletin advising physicians to stop prescribing DES to pregnant women because it was linked to a rare vaginal cancer in female offspring.

Is There a Medical Test for DES Exposure?

No known medical test (such as blood, urine or skin analysis) has been developed that can detect DES exposure. However, the DES Self-Assessment Guide is designed to help you assess whether you might have been exposed to DES.

Who Should Use the DES Self-Assessment Guide?

- **Women** pregnant between 1938 and 1971
- **Women** born between 1938 and 1971
- **Men** born between 1938 and 1971

Note: Women who were BOTH born AND pregnant during 1938–1971 should respond to the statements for both women who were pregnant and women who were born during 1938–1971.

This self-assessment is part of the Centers for Disease Control and Prevention's DES Update – information for you, your family, and your health care provider.

Available at no charge by calling toll-free 1-888-232-6789 or visiting www.cdc.gov/DES.

Known Health Risks of **DES Exposure**

More than 30 years of research have confirmed that health risks are associated with DES exposure. However, not all exposed persons will experience DES-related health problems.

Research published 1971–2002 linked DES exposure with increased health risks:

WOMEN PRESCRIBED DES WHILE PREGNANT. These women are at a modestly increased risk for

- Breast cancer

WOMEN EXPOSED TO DES BEFORE BIRTH (in the womb), known as DES Daughters, are at an increased risk for

- Clear cell adenocarcinoma (CCA) of the vagina and cervix
- Reproductive tract structural differences
- Pregnancy complications
- Infertility

MEN EXPOSED TO DES BEFORE BIRTH (in the womb), known as DES Sons, are at an increased risk for

- Non-cancerous epididymal cysts

What Does the Term “Increased Health Risk” Mean?

Increased risk means that the women and men who were exposed to DES are more likely to have certain health problems than people who were not exposed.

The Self-Assessment will guide you through 4 Steps. **Please turn the page for Step 1.**

DES Self-Assessment Step 1

How Do I Use the Self-Assessment?

The Self-Assessment has 4 Steps. Start with Step 1 on this page.

- Read each numbered statement.
- Mark your personal responses: **Yes/Not Sure (NS)**, **No/Not Applicable (NA)**
- Follow directions in the section, "**What do my responses mean?**" at the bottom of each page.

1. When I was pregnant,* I had regular medical care. **Yes/NS** **No/NA**
2. When my mother was pregnant with me,* she had regular medical care. **Yes/NS** **No/NA**
3. I was prescribed DES when I was pregnant* **Yes/NS** **No/NA**
4. When my mother was pregnant with me,* she was prescribed DES. **Yes/NS** **No/NA**

**during 1938–1971*

How Was DES Given to Pregnant Women?

Women who obtained DES were required to have a physician's prescription filled by a pharmacist, although some physicians gave DES directly to their patients. Therefore, women who were not under a physician's care during their pregnancy most likely did not receive the drug.

Note: DES is sometimes confused with the drug Thalidomide that caused birth defects. Thalidomide was never approved for prescription in the United States. DES was called by different labels. Some of the most common were stilbestrol and DESPlex.

WHAT DO MY RESPONSES MEAN?

If you marked Yes/Not Sure to any of the statements 1–4, continue to STEP 2.

If you marked No/Not Applicable to all statements 1–4, it is unlikely that you were exposed to DES. However, it is still important for you to receive regular health checkups and consult with your health care provider about any potential health problems.

DES Self-Assessment Step 2

All women and men who responded Yes/Not Sure to any of the statements 1–4 should continue to respond to statements 5–8.

5. My mother had at least one miscarriage* before I was born. **Yes/NS** **No/NA**
6. My mother's doctor prescribed medication to treat or help prevent pregnancy problems while she was pregnant with me.* **Yes/NS** **No/NA**
7. I had at least one miscarriage.* **Yes/NS** **No/NA**
8. My doctor prescribed medication while I was pregnant* to treat or help prevent pregnancy problems. **Yes/NS** **No/NA**

**during 1938–1971*

How Did Physicians Decide to Prescribe DES?

Most women who were prescribed DES had a history of miscarriage and/or giving birth prematurely before the pregnancy when they were prescribed DES. DES was prescribed in different forms (most commonly as a pill); but it also was given by injection or as a vaginal suppository.

WHAT DO MY RESPONSES MEAN?

If you marked Yes/Not Sure to any of the statements 5–8, continue to STEP 3.

If you marked No/Not Applicable to all statements 5–8, it is unlikely that you were exposed to DES. However, it is still important for you to receive regular health checkups and consult with your health care provider about any potential health problems.

DES *Self-Assessment Step 3*

**If you are a woman, respond to statements 9–14;
if you are a man, skip these statements and respond to statements 15–17.**

Women PREGNANT between 1938 and 1971

9. I have been diagnosed with breast cancer. **Yes/NS** **No/NA**
10. My daughter has been diagnosed with one or more of the following conditions: clear cell cancer of the vagina or cervix, infertility, ectopic (tubal) pregnancy, miscarriage. **Yes/NS** **No/NA**
11. My son has had non-cancerous growths on the outside of the testicles or other genital abnormalities. **Yes/NS** **No/NA**

Women BORN between 1938 and 1971

12. I have experienced problems becoming pregnant. **Yes/NS** **No/NA**
13. I have had an ectopic (tubal) pregnancy and/or a miscarriage. **Yes/NS** **No/NA**
14. My physician has said that some of my reproductive organs are irregular in shape or structure (for example, a T-shaped uterus). **Yes/NS** **No/NA**

Men BORN between 1938 and 1971

15. I was born with undescended testicles. **Yes/NS** **No/NA**
16. I have had non-cancerous growths on the outside of the testicles (epididymal cysts). **Yes/NS** **No/NA**
17. I have had other genital abnormalities. **Yes/NS** **No/NA**

If I Have a Health Condition Listed Above, Does That Mean I Have Been Exposed to DES?

Not necessarily. People exposed to DES are at an increased risk for developing these conditions, but all of these problems also can occur in persons not exposed to DES.

WHAT DO MY RESPONSES MEAN?

If you marked Yes/Not Sure to any of the statements 9–17, continue to STEP 4.

If you marked No/Not Applicable for all statements 9–17, you have not experienced the known health problems linked to DES exposure. It is still important for you to receive regular health checkups and consult with your health care provider about any potential health problems.

DES *Self-Assessment Step 4*

What Should I Do Next?

Remember that the DES SELF-ASSESSMENT is a guide. Its main purpose is to provide information on the conditions and health risks of DES exposure. The DES SELF-ASSESSMENT cannot determine whether or not you were exposed to DES.

If you have responded Yes/Not Sure to one or more of the 17 numbered statements in Steps 1–3, you have some characteristics or conditions linked to DES exposure and should be aware of the possibility of DES exposure as part of your health history.

- Review the information in each statement where you responded Yes/Not Sure.
- Use the information in those statements to start a discussion about DES with your health care provider, your family, and friends.
- Consult CDC's DES Update available by calling toll-free 1-888-232-6789 or visiting www.cdc.gov/DES. You can also refer to "Additional DES Resources" listed on the back cover.

Suggested Steps for Women Pregnant or Born During 1938–1971 and Men Born during These Years

WOMEN PREGNANT BETWEEN 1938 AND 1971

- Contact your health care provider if you discover breast lumps.
- Be sure to get your recommended mammograms and have regular checkups.
- Discuss DES with your family, especially any child you were pregnant with when you might have been prescribed DES.

WOMEN BORN BETWEEN 1938 AND 1971

- Schedule regular gynecological exams, including a Pap test, pelvic exam, clinical breast exam, and recommended mammogram.

MEN BORN BETWEEN 1938 AND 1971

- Contact your health care provider if you feel lumps in your testicles.

Additional DES *Resources*

Use the contact information for these organizations and agencies to find out more about DES-related health risks and to locate free or low-cost health screenings.

Centers for Disease Control and Prevention

4770 Buford Highway NE, Mailstop F-29
Atlanta, GA 30033
Toll-free: 1-888-232-6789
Web site: www.cdc.gov/DES

CDC's Reproductive Health Information Source

Women's reproductive health;
Men's reproductive health;
Research and scientific reports
Web site: www.cdc.gov/nccdp/rdh/

CDC National Breast and Cervical Cancer Early Detection Program

A service providing information about where you can get a free or low-cost mammogram or Pap test.
Toll-free: 1-888-842-6355
Web site: www.cdc.gov/cancer/nbccedp/index.htm

Center for Medicare and Medicaid Services –

The following publications are available.
“Your Medicare Benefits”
“Women with Medicare – Visiting Your Doctor for a Pap Test, Pelvic Exam, and Clinical Breast Exam”
“Medicare Preventative Services to Keep You Healthy”
Toll-free: 1-800-MEDICARE (1-800-633-4227)
Web site: www.medicare.gov

DES Action USA

610 16th Street, Suite 301
Oakland, CA 94612
Toll-free: 1-800-DES-9288 (1-800-337-9288)
Phone: 510-465-4011
Fax: 510-465-4815
Web site: www.desaction.org
E-mail: desaction@earthlink.net

DES Sons Network

104 Sleepy Hollow Place
Cherry Hill, NJ 08003
E-mail: msfreilick@hotmail.com

DES Cancer Network

P.O. Box 220465
Chantilly, VA 20153-0465
Toll-free: 1-800-DESNET4 (1-800-337-6384)
Phone: 202-628-6330
Fax: 202-628-6217
Web site: www.descancer.org
E-mail: desnetwrk@aol.com

National Cancer Institute's Cancer Information Service

A service providing information on all types of cancer.
Toll-free: 1-800-4-CANCER (1-800-422-6237)
TTY Line: 1-800-332-8615
Web site: www.cancer.gov

Where Can I Get Additional Copies of the DES Self-Assessment?

You can request printed copies by calling CDC's toll-free number 1-888-232-6789. The Self-Assessment is also available online at CDC's DES Update Web site at www.cdc.gov/DES.