

PROTECTING YOUR HEALTH AND THE HEALTH OF YOUR FAMILY

Women Prescribed DES While Pregnant

Women prescribed DES while pregnant are at a modestly increased risk for breast cancer. They should be screened for breast cancer with the same tests and at the same intervals as women in the general population. The following are action steps you can take to protect your health.

- **Have clinical breast exams and regular mammograms**

Most health care providers recommend that women 40 years of age and older have a mammogram (an X-ray of the breast) every 1–2 years. In addition, most health care providers perform clinical breast examinations (visual and manual examination of the breast) during routine physical examinations. Additional guidelines for breast cancer screening can be found at the National Cancer Institute (NCI) Web site (www.cancer.gov) or the American Cancer Society (ACS) Web site (www.cancer.org). A description of mammography can be found at the ACS Web site by typing “mammography” in the search box on the home page and then clicking on the link to the Glossary and typing “mammography” in the cancer-related terms box.

- **Perform monthly breast self-exams**

Most health care providers recommend that you learn and practice monthly breast self-examination as a way to detect any lumps in your breasts, discharge from the nipples, or skin changes (such as dimpling or puckering). Instructions for breast self-examination can be found at the ACS Web site by typing “breast self-exam” in the search box on the home page and then clicking on the link “How to Perform a Breast Self-Exam.”

- **Talk with your family, especially your children, about DES**

If you have not already discussed it, you may find it difficult to tell your children they were exposed to DES. However, many mothers feel a sense of relief after telling their children; family members need to know whether they were exposed to DES. Once your children know about their exposure, they can get proper medical care to protect their health now and in the future.

- Encourage your children to notify their health care provider about their DES exposure before birth (in the womb).
- Request copies of CDC’s DES Update to share with your children. Visit CDC’s DES Web site at www.cdc.gov/DES or call toll-free 1-888-232-6789.

- **Share the DES Self-Assessment**

As you talk with others about DES, they may wonder whether they were exposed to DES. To assess whether they may have been exposed to DES, refer to the section of CDC’s DES Update titled [DES SELF-ASSESSMENT: A Guide to Understanding Your Risk for DES Exposure](#).

- **Stay up-to-date on DES research**

Researchers continue to study DES and will learn more health information about DES exposure in follow-up studies. For more information refer to the section of CDC’s DES Update titled [WHAT WE ARE LEARNING ABOUT DES: Recent DES Research](#).

- **For more information about**

- DES exposure and related health risks, visit CDC's DES Update Web site at www.cdc.gov/DES or call toll-free 1-888-232-6789.
- Breast cancer risk for women prescribed DES while pregnant, refer to the sections of CDC's DES Update titled [WHAT WE ARE LEARNING ABOUT DES: Recent DES Research](#), and [ADDITIONAL DES RESOURCES: DES Bibliography](#).
- Breast cancer causes and prevention, visit the National Cancer Institute (NCI) Web site at www.cancer.gov or call the Cancer Information Service (CIS) toll-free 1-800-4-CANCER (1-800-422-6237). The American Cancer Society (ACS) also provides detailed information about breast cancer screening at their Web site (www.cancer.org).

PROTECTING YOUR HEALTH AND THE HEALTH OF YOUR FAMILY

Women Exposed to DES Before Birth (in the Womb), known as DES Daughters

DES Daughters are at an increased risk for clear cell adenocarcinoma (CCA) of the vagina and cervix, cervical intraepithelial neoplasia (CIN), reproductive tract structural differences, pregnancy complications, pre-term delivery, and infertility and therefore should be monitored throughout their lifetimes. The following are steps you can take to protect your health.

- **Schedule regular gynecological exams, including Pap test and pelvic exam**

The National Cancer Institute (NCI) published a description of appropriate pelvic examinations for DES Daughters. Pelvic examinations for DES Daughters should be performed in a similar manner as those performed among unexposed women.

Pelvic examinations in DES Daughters should include

- careful visual examination and palpation (feeling) of the vagina and cervix with rotation of the speculum so that all vaginal walls can be inspected;
- Pap smears from the cervix and the surfaces of the upper vagina; and
- iodine staining of the vagina and cervix or a colposcopy, depending on the detection of any abnormalities during the examination. Iodine staining allows your health care provider to evaluate changes in the cervix or vagina. A colposcopy uses a device that works like a magnifying glass, allowing your health care provider to carefully check the vagina and cervix. Your health care provider may take photographs using the colposcope so that any changes in your condition can be monitored during future examinations.

- **Schedule clinical breast exams and regular mammograms**

Studies have not found a statistically significantly increased risk of breast cancer among DES Daughters of all ages. However, a recent study did find significantly increased risk among DES Daughters over age 40 (Palmer, 2002). Since this was the first study to identify a link, research will continue to see if results will be repeated and to determine if DES Daughters of other ages also have a greater risk of breast cancer. While research continues, DES Daughters should be screened for breast cancer with the same tests and at the same intervals as women in the general population. The following actions can help you protect your health.

- Most health care providers recommend that women 40 years of age and older have a mammogram (an X-ray of the breast) every 1–2 years.
- In addition, most health care providers perform a clinical breast examination (visual and manual examination of the breast) during routine physical examinations. Guidelines for breast cancer screening can be found at the National Cancer Institute (NCI) Web site (www.cancer.gov) or the American Cancer Society (ACS) Web site (www.cancer.org). A description of mammography can be found at the ACS Web site by typing “mammography” in the search box on the home page and then clicking on the link to the Glossary and typing “mammography” in the cancer-related terms box.

- **Perform monthly breast self-exams**

Most health care providers suggest that, in addition to getting recommended mammograms, you learn and practice monthly breast self-examination as a way to detect any lumps in your breasts, discharge from the nipples, or skin changes (such as dimpling or puckering). Instructions for breast self-examination can be found at the ACS Web site by typing “breast self-exam” in the search box on the home page (www.cancer.org) and then clicking on the link “How to Perform a Breast Self-Exam.”

- **Obtain information regarding low-cost or free screening**

To find out where you can get a free or low-cost Pap test or mammogram, visit CDC’s National Breast and Cervical Cancer Early Detection Program Web site at <http://www.cdc.gov/cancer/nbccedp/index.htm> or call toll-free 1-888-842-6355.

- **Seek infertility counseling if you have difficulty becoming pregnant**

DES Daughters are at an increased risk of infertility. Your health care provider should be informed about your pregnancy plans so that he or she can communicate to you the risks of infertility. Although no single test, treatment, or screening is necessary because of your DES exposure, your health care provider may recommend that you undergo certain tests or screenings appropriate for your risk. For example, your health care provider may perform a hysterosalpingogram. This is an X-ray that can check for structural differences and physical alterations in your upper genital tract.

- For more information about infertility, refer to the section of CDC’s DES Update titled [ADDITIONAL DES RESOURCES: Partner and Government Organizations](#).

- **Treat pregnancies as “high risk”**

DES Daughters are at an increased risk of pregnancy complications and should be sure that their health care providers consider their pregnancies “high risk” and establish an appropriate plan of action. Your provider may suggest more frequent check-ups or tests to ensure that your pregnancy is progressing properly.

- **Talk with your family, especially your children, about DES**

Research on the health risks of the third generation (the offspring of DES Daughters and Sons) is just beginning, and the results are preliminary. Research will continue as these children age. If future research identifies health risks for the third generation, informing them about their DES exposure will become even more important. To help protect your child’s health, consider taking the following steps.

- Note your DES exposure on your child’s health record. For a DES health information form, refer to the section of CDC’s DES Update titled [WHAT YOU CAN DO ABOUT DES: DES Health Information Record](#).
- Notify your child’s health care provider about your exposure to DES.
- To learn more about the ongoing research of the third generation, refer to the section of CDC’s DES Update titled [WHAT WE ARE LEARNING ABOUT DES: Recent DES Research](#).
- Request copies of CDC’s DES Update to share with your children. Visit CDC’s DES Update Web site at www.cdc.gov/DES or call toll-free 1-888-232-6789.

- **Share the DES Self-Assessment**

As you talk with others about DES, they may wonder whether they were exposed to DES. To assess whether you or others may have been exposed to DES, refer to the section of CDC's DES Update titled [DES SELF-ASSESSMENT: A Guide to Understanding Your Risk for DES Exposure](#). For additional copies of the DES Self-Assessment, visit CDC's DES Update Web site at www.cdc.gov/DES or call toll-free 1-888-232-6789.

- **Stay up-to-date on DES research**

Researchers continue to study DES and may learn more about the health effects of DES exposure. For more information, refer to the section of CDC's DES Update titled [WHAT WE ARE LEARNING ABOUT DES: Recent DES Research](#).

- **For more information about**

- DES exposure and related health risks, visit CDC's DES Update Web site at www.cdc.gov/DES or call toll-free 1-888-232-6789.
- Health risks for DES Daughters, refer to the sections of CDC's DES Update titled [WHAT WE KNOW ABOUT DES: Known DES Health Effects](#); [WHAT WE ARE LEARNING ABOUT DES: Recent DES Research](#); and [ADDITIONAL DES RESOURCES: DES Bibliography](#).

PROTECTING YOUR HEALTH AND THE HEALTH OF YOUR FAMILY

Men Exposed to DES Before Birth (in the Womb), Known as DES Sons

DES Sons have an increased risk of non-cancerous epididymal cysts (growths on the testicles). The following are steps you can take to protect your health.

- **Perform monthly testicular self-exams**

Researchers continue to study whether DES exposure is linked with an increased risk of developing testicular cancer. Talk with your health care provider about whether monthly testicular self-examinations should be a part of your regular health activities. For information about how to do a testicular self-exam, refer to the American Cancer Society's (ACS) Web site (www.cancer.org).

- **Talk with your family, especially your children, about DES**

Research on the health risks for the third generation (the offspring of DES Daughters and Sons) is just beginning. Research will continue on these children as they age. If future research identifies health risks to the third generation, informing them about their DES exposure will become even more important. To help protect your child's health, consider taking the following steps.

- Note your DES exposure on your child's health record. For a health information form, refer to the section of CDC's DES Update titled [WHAT YOU CAN DO ABOUT DES: DES Health Information Record](#).
- Notify your child's health care provider about your exposure to DES.
- To learn more about the ongoing research of the third generation, refer to the section of CDC's DES Update titled [WHAT WE ARE LEARNING ABOUT DES: Recent DES Research](#).
- Request copies of CDC's DES Update to share with your children. Visit CDC's DES Update Web site at www.cdc.gov/DES or call toll-free 1-888-232-6789.

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