What DES Daughters and their doctors need to know about the lifelong risks of DES exposure to have a discussion about DES health care needs and concerns.

This toolkit is derived from the evidence-based research and clinical practice recommendations of respected national institutions and includes the following information:

- Adverse Health Effects due to DES Exposure
- CDC DES Daughter Pap/pelvic Exam Protocol
- Screening Guidelines for frequency of exams or follow-up care

DES (diethylstilbestrol) is a synthetic estrogen given as an anti-miscarriage drug to millions of pregnant women, primarily from 1938–1971, but not limited to those years. Female offspring, DES Daughters, are at risk for certain health problems.

Screening Recommendations:

1. Special DES Daughter Pap/pelvic Exam Done Annually (directions inside)
   - to check for clear cell adenocarcinoma (CCA) of the vagina and/or cervix since DES Daughters are at a lifetime risk 40 times higher than unexposed women (Hoover, et al., N Engl J Med 2011; 365:1304-1314)
     - While a rare disease, even for DES Daughters, this population is aging and CCA can occur after menopause
   - An important aspect of the special exam is palpation of the vagina to check for cancerous lumps under the surface
   - Even after a hysterectomy or menopause DES Daughters should continue with this annual exam to screen for vaginal cancer

2. Vigilance in Breast Cancer Screenings as DES Daughters Age Past Forty
     - Annual breast screenings
     - Yearly clinical breast exams
     - Attention to breast health by DES Daughters who alert providers to changes

Treatment Considerations:

1. Treatments for DES Daughters are the same as for unexposed women in most areas
   - The exception is for gynecologic procedures because cervical stenosis is a concern in this population, especially from cryosurgery and cone biopsy, which the researchers suggest should be approached cautiously (Cervical Stenosis Following Minor Gynecologic Procedures on DES-Exposed Women, Obstetrics & Gynecology 56:33, Sept. 1980)
     - DES knowledgeable providers are favoring LEEP for DES Daughters, understanding the least invasive but diagnostically correct procedure is the goal
Annual Exam for DES Daughters

Although health effects of DES exposure differ among DES Daughters, health care providers should monitor these women for abnormal genital tract structures, particularly for clear cell adenocarcinoma (CCA) of the vagina and cervix.

- Clinical breast exam
- Vulvar inspection
- Vaginal and cervical inspection
  - Inspection of epithelial surfaces of vagina
  - Rotation of speculum to view anterior & posterior walls of vagina
- Cytology
  - Separate specimens from vagina fornices and cervix — all specimens placed on one slide or in liquid media
- Palpation of vagina and cervix (an essential part of the exam)
  - Palpate entire length of vagina, including fornices
  - Note ridges or structural changes
- Bimanual rectal-vaginal exam
- Biopsy
  - Areas of thickening or induration found during vaginal and cervical palpation
  - Palpable nodules
  - Discrete areas of varied colors or textures
  - Atypical colposcopic findings
- Colposcopy
  - If abnormal findings on Pap smear
- Iodine staining of vagina and cervix
  - To confirm boundaries of epithelial changes
  - Use Lugol’s solution (half strength)
- Frequency of follow-up visits
  - Determine on individual basis
  - Focus on changes since initial evaluation — include: palpation, inspection, cervical & vaginal cytology
  - Colposcopy, iodine staining, biopsy as needed
  - Ask about interval bleeding or abnormal vaginal discharge
DES Daughters Should Have Annual Paps

Current cervical cancer screening guidelines released in March 2012 by the U.S. Preventive Services Task Force (USPSTF) specify that some women can skip years between Paps, but not DES Daughters.

The third paragraph under USPSTF Recommendations spells out that:

“This recommendation statement does not apply to women with in utero exposure to diethylstilbestrol.”

However, we are watching the evolution of screening protocols and detect a movement toward potentially allowing DES Daughters over age 70 to lengthen the time between cervical cancer screenings, if there has been no previous diagnosis of cancer or recent cervical or vaginal biopsies or changes. If new Pap recommendations are issued, yearly visits to a gynecologist would still be needed, even without a yearly Pap or cervical cancer screening. Even after hysterectomy it’s prudent for DES Daughters to be checked for vaginal cancer. DES Action will keep members informed of official guideline changes, to pass along to providers.

In early years of caring for DES Daughters colposcopy exams were routinely performed. Some DES Daughters continue to have them. However, thinking has evolved now so providers generally employ colposcopy primarily as a diagnostic tool:

“A routine cervical Pap test is not adequate for DES Daughters. The Pap test must gather cells from the cervix and the vagina. It is also good for a clinician to see the cervix and vaginal walls. They may use a colposcope to follow-up if there are any abnormal findings.”


Menopause and Hormone Replacement Therapy

NCI DES Follow-up Study research indicates that DES Daughters may begin menopause slightly earlier than unexposed women. However, it appears their experiences are no different from unexposed populations.

Studies have not been done specifically concerning DES exposure and HRT use. But since DES Daughters were exposed to a synthetic hormone in utero, and knowing of current studies on HRT concerns, it may be considered prudent to use the lowest dose for the shortest period of time if symptom relief is absolutely needed.
Researchers with the National Cancer Institute (NCI) DES Follow-up Study outlined twelve known adverse health impacts for DES Daughters in the October 6, 2011 issue of the New England Journal of Medicine (“Lifetime burden of adverse health outcomes among women exposed in-utero to Diethylstilbestrol (DES),” Hoover et al. N Engl J Med 2011; 365:1304-1314)

Higher Incidence Percentage in DES Daughters and DES Sons Compared with Unexposed Population

<table>
<thead>
<tr>
<th>Condition</th>
<th>DES-Exposed</th>
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</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>21%</td>
</tr>
<tr>
<td>High Cholesterol</td>
<td>12%*</td>
</tr>
<tr>
<td>Hypertension</td>
<td>14%*</td>
</tr>
<tr>
<td>Coronary Artery Disease</td>
<td>18%</td>
</tr>
<tr>
<td>Myocardial Infarction</td>
<td>28%</td>
</tr>
<tr>
<td>Stroke</td>
<td>55%</td>
</tr>
<tr>
<td>All CVD</td>
<td>27%*</td>
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<tr>
<td>Osteoporosis</td>
<td>24%</td>
</tr>
<tr>
<td>Fractures</td>
<td>30%</td>
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</tbody>
</table>

*Difference between exposed and unexposed is statistically significant (i.e., unlikely to be due to chance) but doesn’t prove DES was causal.

DES research continues with additional health issues now possibly linked to exposure. At this time there are no special screenings or treatments identified, just the need for awareness of potential increased risks.

(“Medical Conditions Among Adult Offspring Prenatally Exposed to Diethylstilbestrol,” Troisi et al. Epidemiology; Vol. 24, No. 3, May 2013)

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The mission of DES Action USA is to identify, educate, empower and advocate for DES-exposed individuals