

# Basic Care for DES Mothers, Daughters and Sons: An Update

by Judith Turiel, Ed. D., Research Liaison

**A**s DES-exposed women and men, we are always interested in new information about DES-related health effects and about new health care recommendations. However, we also need to remind ourselves periodically about the basic, ongoing health monitoring we require because of our DES exposure. Though we may have heard many times about the health care we should obtain regularly, these routine, lifelong needs may be just the ones we tend to overlook, deny, or conveniently forget. In fact, recent medical reports reaffirm the importance of following established health care recommendations throughout our lifetime. The following article provides a friendly reminder about basic

health care needs.

## DES Daughters

**T**he initial discovery of a rare vaginal cancer in young women exposed to DES before birth—clear cell adenocarcinoma—was the stimulus for recommendations about gynecologic monitoring of DES daughters. Regular gynecologic exams should include:

- **Pap smears of the vagina and cervix (see article on page 1 for further information on obtaining the type of Pap test that is required for a DES daughter).**
- **Careful palpation, or feeling, of the vaginal wall. The gynecologist uses his or her fingers to feel for lumps that would require a biopsy.**

- **Colposcopy (viewing the vagina and cervix through a magnifying instrument) to look for tissue that appears abnormal.**
- **Biopsy of any suspicious areas.**

DES daughters should seek a gynecologist who has experience performing this DES exam (for example, a regular Pap is not adequate), and who will send her Paps and biopsies to a laboratory that has experience evaluating material from DES-exposed individuals.

One recent medical report (Kramer et al, "Diethylstilbestrol-Related Clear-Cell Adenocarcinoma in Women With Initial Examinations Demonstrating No

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## A Closer Look at the Pap Test

by Candice Tedeschi, RNC, Board Member

**What is the Pap Test and Why is it Important?**

**W**hen detected in its early stages, cervical cancer is one of the most curable cancers. In the 1930s, Dr. George Papanicolaou developed a simple screening exam for testing cervical cancer.

The now familiar test that bears a shortened reference to his name—the Pap smear—is part of a routine gynecologic check-up. A speculum is inserted into the vagina so that the cervix and walls of the vagina can be seen by the examiner. Smears, or

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## Get Into Action

DES Action USA could not have originated and grown without the dedicated efforts of volunteers. Today, we proudly boast the activities of over forty DES Action groups across the country and around the world. The foundation of each group was created and nurtured by volunteers. *We still need you.* Write your group today. Offer your services for a few hours a week.

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**BASIC CARE** from page 1. . .

*Malignant Disease," Obstetrics and Gynecology*, June 1987) emphasizes the need to repeat the above health care measures every six months. (If a DES daughter has several exams with no problems detected, some physicians perform the colposcopy once a year, maintaining the rest of the exam twice a year.) The Kramer article described four DES daughters, ranging in age from 16 to 31 years old, who developed clear cell adenocarcinoma during the time they were receiving regular DES gynecologic exams. Although a DES daughter is unlikely to develop this rare cancer (approximately one daughter out of 1,000 by her mid-thirties), there is no way to predict the individuals who will. Therefore, all DES daughters must be watched carefully. And, although clear cell cancer is most frequently diagnosed among DES daughters who are in their late teens or early twenties, cases do arise among women in their thirties. Furthermore, no information is available about the rate of vaginal or cervical adenocarcinoma among DES daughters as they approach and pass menopause, the age at which such tumors do become more common in the general population. As the Kramer article concludes, "until more data become available, (DES daughters) should be followed indefinitely."

While the rare, DES-associated vaginal cancer has been the main focus of gynecologic recommendations, regular DES exams are also aimed at detecting a different type of cervical or vaginal

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## Cervicography

by Candice Tedeschi, RNC, Board Member

**C**urrent gynecologic recommendations for DES-exposed women include cervical and vaginal Pap smears, vaginal palpations and at least yearly colposcopy. In rural areas or cities where these services are not readily available, a new technique—the cervigram—may be a useful alternative.

The technique combines principles of colposcopy and a photographic procedure, called cervicography. After insertion of a speculum, a Pap smear is taken in the usual manner (remember: in DES-exposed women, that includes a four-quadrant vaginal smear). The cervix and vagina are rinsed with a weak vinegar solution and a photo is taken with a specially designed 35 mm camera and ring flash attachment. As with colposcopy, nothing touches the patient, so the procedure is painless.

The film is sent to a physician who is a colposcopic expert and will interpret the photo, then report back to the original health care provider. If any abnormalities are seen, biopsies can be taken and/or the woman can be referred for a direct colposcopy.

### Disadvantages of Cervicography

- The camera must be purchased from National Testing Labs (NTL), in St. Louis, and cervigrams must be read by a designated expert of NTL. Con-

cern: how much experience does the expert have with DES-exposed women? (NTL will try to provide a DES-knowledgeable M.D.)

- The vagina, with all of its folds, is not easy to photograph; some areas will be missed.

- There is a relatively high false positive rate (cervigram shows something suspicious, but a biopsy reveals nothing), due mainly to lack of experience and/or lack of adequate patient history information.

- If the cervigram shows suspicious areas, the patient must then be sent for colposcopy and/or biopsy, which could increase the anxiety and cost to the patient.

### Advantages of Cervicography

- Cervicography can be done by a nurse or physician.

- The health care provider does not need to be trained in the use of a colposcope; cervigrams are interpreted by knowledgeable experts.

- The camera is less expensive to buy than a colposcope, so more health care providers can use it, especially in rural areas. The decreased cost of an exam could be passed on to the patient.

- The accuracy of the cervigram appears to be equal to the colposcope.

- The procedure provides permanent photos that can be kept in the patient chart for comparison from year to year.

## Expanded Medicare Coverage for Mammographies Approved

**T**he Catastrophic Illness Bill, recently passed by Congress, provides Medicare coverage up to \$50 for mammography screening. This is an important change over the previous rule, which covered only diagnostic procedures and not annual routine checkups.

Unfortunately, total cost coverage of mammographies is not guaranteed; if a patient's mammography bill is greater than \$50, she must pay the difference. However, the new law provides an important start in making an important examination more accessible to women.

The expanded Medicare coverage begins in 1989 and will pay for annual screenings for women between the ages of 49 and 64 and biannual screenings for women over 64. The Secretary of Health has the authority to revise this schedule. Consumers can write to him at the address below if they would like the ruling expanded to include annual screenings for women over age 64.

Dr. Otis Bowen  
Secretary of Health  
Department of Health and Human Services  
200 Independence Ave., SW  
Washington, D.C. 20201

## Civil Justice Foundation Grant Helps Support Physician Referrals

DES Action recently received a \$3,500 grant from the Civil Justice Foundation to help support our project to expand physician referral listings in states without DES Action locals. If you live in a state other than those mentioned on p. 2, and your physician is both DES-knowledgeable and provides skillful and sensitive care, you can help us with this vital work. Please send the name, address and phone number of your doctor to our San Francisco office.



**BASIC CARE** from page 2 . . malignancy or condition that may be pre-malignant: squamous cell neoplasia. This is sometimes called cervical or vaginal intraepithelial neoplasia (CIN and VIN), or dysplasia. These conditions, considered cancer only in their most severe forms, are not associated specifically with prenatal DES exposure. All women are urged to receive regular Pap tests in order to detect squamous cell cervical cancer early. However, in 1984 a large study indicated that DES daughters are twice as likely as non-exposed women to develop cervical and vaginal dysplasia. A recent report (Bornstein et al, "Human Papillomavirus Associated with Vaginal Intraepithelial Neoplasia in Women Exposed to Diethylstilbestrol in Utero, *Obstetrics and Gynecology*, July 1987) describes five DES daughters who developed squamous cell dysplasia in the vagina (VIN), a less common location. It

**"...in 1984 a large study indicated that DES daughters are twice as likely as non-exposed women to develop cervical and vaginal dysplasia."**

is essential to remember that the abnormal cell growth detected by a Pap test may not progress to cancer. Treatment, with its cost and potential for complications, is not always necessary. Rather, mild to moderate dysplasia (CIN or VIN) can be followed closely over time to see whether or not it becomes more severe. Because

diagnosis of these conditions is sometimes more difficult in a DES-exposed woman, she needs to be sure her gynecologist and laboratory have experience with the complexities of DES exposure. Biopsy material can be sent for analysis to a medical center with DES specialists, if needed, before deciding about treatment. (Contact the national office in San Francisco for further information on this.)

### DES Sons


**T**here are no recommendations for regular, ongoing monitoring of DES sons by a urologist that are similar to the gynecologic recommendations for daughters. No increase in reproductive tract cancer has been demonstrated in DES sons that would necessitate regular urologic exams. Unfortunately, there have been few studies of sons, so our information is limited. Some research does link prenatal hormone exposure (including oral contraceptives, hormonal pregnancy tests and DES) to increased risk of testicular cancer. Other studies indicate that DES sons have more reproductive tract structural abnormalities (for example epididymal cysts) than non-exposed men, and may experience more fertility problems. Basic health care recommendations urge DES sons to perform testicular self-exams on a regular basis in order to check for unusual lumps, and to consult a urologist if any type of problem arises (a possible lump, fertility problem, urinary or prostate problem). (Write to our national office in San Francisco for a copy of our free brochure on DES sons and self-exam.)

In the absence of information

## Third Generation Effect of DES?

We have been receiving an increasing number of questions from individuals concerned about whether there will be a "third generation" effect on children of DES daughters and sons.

The one known health effect to the third generation is due to premature birth. This is known as DES-related birth injury. DES daughters are at increased risk of delivering their babies too early. To try to prevent this type of third generation problem, DES daughters should receive high-risk prenatal care (see *Voice* Issue #36).

On the question of whether DES exposure in utero could have affected a daughter's eggs or a son's sperm, that is, made changes in chromosomes, no studies have been done on this subject. We do not know whether this kind of effect will be seen as such offspring mature. 

on longterm health consequences related to prenatal DES exposure in men, we must look to research with laboratory animals for hints about potential DES effects. Two recent studies with mice underscore the importance for DES sons to monitor their own health and report any suspected problem to their physician. One study found an increase in testicular tumors among DES-exposed mice compared to non-exposed animals (Newbold et al, "Testicular Tumors in Mice Exposed in

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## Four New DES Action International Affiliates Starting in Europe

The European campaign on DES is well under way, most recently including a two-day conference in Brussels under the theme "50 Years of



DES—50 Years Too Many." Sponsored by DES Aktiegroep of the Netherlands and the

Green Alternative European Link in the European Parliament, the meetings brought together women from Spain, France, Great Britain, Ireland, Germany, Belgium and the Netherlands. Reports were presented on the medical, governmental and consumer issues related to DES.

Attendees also were informed about a resolution on DES, introduced into the European Parliament. This statement calls on the European Economic Commission to ban the use of DES, prevent its production and export to the Third World, start an information campaign for the public and medical providers, work to trace those exposed since 1947, and study the feasibility of requiring compensation from drug companies.

The conference had the best possible result: women from Spain, Belgium, Ireland and England pledged to start campaigns in each of their countries to inform the public about DES. DES Aktiegroep will coordinate these efforts as well as work to secure European funding for the projects.

## Breast Self-Exam: A Three-Step Process

### 1. In the shower:

Examine your breasts during bath or shower; hands glide easier over wet skin. Fingers flat, move gently over every part of each breast. Use right hand to examine left breast, left hand for right breast. Check for any lump, hard knot or thickening.

### 2. Before a mirror:

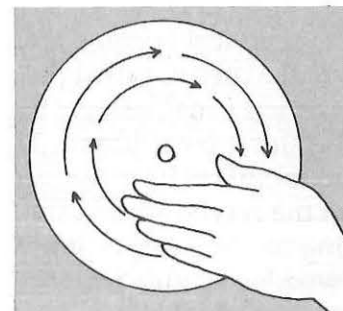
Inspect your breasts with arms at your sides. Next, raise your arms high overhead. Look for any changes in contour of each breast, a swelling, dimpling of skin or changes in the nipple.

Then, rest palms on hips and press down firmly to flex your chest muscles. Left and right breast will not exactly match — few women's breasts do.

Regular inspection shows what is normal for you and gives you confidence in your examination.

### 3. Lying down:

To examine your right breast, put a pillow or folded towel under your right shoulder. Place right hand behind your head — this distributes breast tissue more evenly on the chest. With left hand, fingers flat, press gently in small circular motions around an imaginary clock face. Begin at outermost top of your right breast for 12 o'clock, then move to 1 o'clock, and so on around the circle back to 12. A ridge of firm tissue in the lower curve of each breast is normal. Then move in an inch, toward the nipple, keep circling to examine *every part of your breast*, including nipple. This requires at least three more circles. Now slowly repeat procedure on your



left breast with a pillow under your left shoulder and left hand behind head. Notice how your breast structure feels.

Finally, squeeze the nipple of each breast gently between thumb and index finger. Any discharge, clear or bloody, should be reported to your doctor immediately.

Follow the same procedure once a month about a week after your period, when breasts are usually not tender or swollen. After menopause, check breasts on the first day of each month. After hysterectomy, check with your doctor or clinic for an appropriate time of the month.

If you experience any of the following cancer warning signals, contact your doctor:

- Change in bowel or bladder habits
  - A sore that does not heal
  - Unusual bleeding or discharge
  - Thickening or lump in breast or elsewhere
  - Indigestion or difficulty in swallowing
  - Obvious change in wart or mole
  - Nagging cough or hoarseness
- (Information provided by the American Cancer Society.)

## V O I C E

PAP from page 1...

samples, of cells are taken from the cervix and placed on glass slides; the cells are then sprayed with, or placed in, a preservative. The first sample is usually taken from the cervical opening that leads to the uterus, called the endocervical canal, using a moistened cotton-tip applicator. The second sample is from the outer part of the cervix, around the opening to the vagina, using a little wooden spatula (resembling a popsicle stick).

In addition to this cervical Pap, which all women need on a regular basis, DES daughters should have a sample of cells taken from the four walls of the vagina; this "four quadrant Pap" is also done with a wooden spatula. Because of the DES-related risk of vaginal cancer, four quadrant vaginal smears are an essential part of a DES daughter's routine gynecologic exam. Without them, the areas most susceptible to malignant cell changes will be missed.

### Pap Smear Interpretation

Pap slides are sent to a laboratory, where a technician (called a

cytotechnologist) inspects them to detect any abnormal-looking cells. If any abnormality is seen, the samples are given to a cytopathologist for further analysis, to determine the type of abnormality. Some labs use a number scale for interpreting the slides:

**Class I:** completely normal

**Class II:** abnormal, atypical, inflammatory, often due to infection

**Class III:** abnormal cells, suspicious of pre-malignant condition, usually classified as dysplasia, (mild, moderate or severe) or CIN (cervical intra-epithelial neoplasia) I, II, III

**Class IV:** probably malignant cells, usually classified as (CIS) carcinoma in situ or severe dysplasia, or CIN III

**Class V:** malignant cells

Many labs around the country are switching from a number classification to written descriptions of the smear. Such descriptions give the labs more flexibility in reporting their findings, and provide the health care provider with more information about the individual patient's results.

Interpretation of Pap smears from DES daughters can be more complicated, since DES exposure results in various kinds of cell changes. While some of these changes indicate the very rare cancer, others are non-malignant cell changes which do not require treatment. A lab experienced in analyzing DES daughters' Pap smears, therefore, can help avoid unnecessary treatment, as well as detect vaginal or cervical cancer.

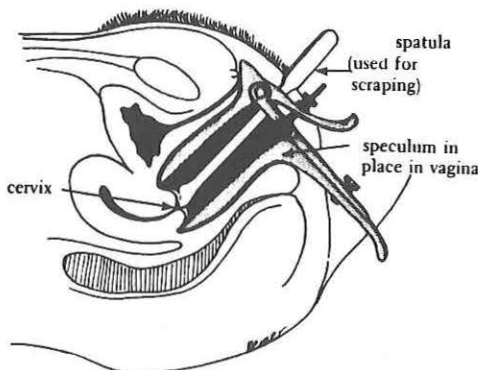
### Problems With the Pap Test

Beyond DES-specific complexities of interpretation, Pap tests do have unacceptably high rates of "false negative" results (reported as normal when abnormal cells are actually present). Reasons for inaccurate results include:

- Errors at the time smears are taken. For example, if abnormal cells are high in the endocervical canal, the cotton-tipped applicator may not reach them. (For DES-exposed women with pinpoint-sized cervical openings, a possible solution is the new cytobrush, which looks like a mascara wand and can penetrate a very small cervical opening.)
- Abnormal areas that don't shed enough cells to be picked up.
- Cells left to air dry instead of sprayed with a preservative.
- Failure by care providers to include with the slides information about the patient that affects slide interpretation. This includes age, last menstrual period, any current symptoms, past history of abnormal Pap smears or treatment.
- Taking smears during a woman's period, or following her use of a douche, lubricant or spermicidal jelly. (Women should avoid these for 24-28 hours before their exam, since they can distort or wash away cells.)
- Use of high-volume, cut-rate laboratories that specialize in fast reporting of Pap smear results—a specialty begging for mistakes.

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### Placement of Speculum for a Pelvic Exam





PAP from page 6...

### How You Can Help Assure An Accurate Pap Test

1. Double-check that your provider does a four-quadrant vaginal Pap along with cervical smears.
2. Ask if she or he uses a cytobrush, especially if you have a small cervical opening or previous treatment on your cervix.
3. Ask which laboratory analyzes your slides.
  - Is the lab accredited by the American Society of Cytology?
  - Is the lab nearby? If not, why not?
  - Are they experienced with smears from DES daughters?
  - Can you consult with the lab director, if you wish, about who interpreted your Pap?
  - Can you obtain a copy of your Pap result?
4. If you have any question about results and/or the need for treatment, your slides can be sent to a DES specialist for interpretation (as can biopsy material).

### letter to the editor

Dear Editor,

Just wanted to let you know that as a DES daughter, I've been trying to get pregnant for four years. Last week I found out that I was finally pregnant. I have been seeing a wonderful specialist for three years who always gave me the hope I needed.

After deciding to skip a month between artificial inseminations, I went ahead and tried a home remedy (read about in *Our Bodies, Ourselves*) of douching with baking soda one half hour before intercourse on my fourteenth day (day of ovulation). I just had to let you know, in case this might help even one other woman.

Good luck to all DES exposed! Thanks for all those wonderful experiences that have been told in the *Voice*. They really made me realize that I wasn't alone.

Joyce T.



The following is a list of books recently acquired by DES Action. We will be reviewing some of these publications in future issues of the *Voice*, but until then include them here for your information.

*Invisible Scars: A Guide to Coping with the Emotional Impact of Breast Cancer*, by Mimi Greenberg, Ph.D. (Walker and Company, 1988), \$17.95.

*Made to Order: The Myth of Reproductive and Genetic Progress*, edited by Patricia Spallone and Deborah Lynn Steinberg. (Pergamon Press, 1987), \$16.50.

*Overcoming Endometriosis*, by Mary Lou Ballweg and the Endometriosis Association. (Congdon and Weed, 1987), \$9.95.

*Worse Than the Disease: The Pitfalls of Medical Progress* by Diana Dutton. (Cambridge University Press, 1988), \$29.95.



## Join DES Action!



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☐ Please keep my name anonymous.

I am a: ☐ DES Daughter ☐ DES Son ☐ DES Mother ☐ other

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**BASIC CARE** from page 2. . . Utero to DES," *Journal of Urology*, December 1987). The other report describes structural alterations of human prostate tissue grafted, and allowed to grow, in DES-exposed mice (Sugimura et al, "Temporal and Spatial Factors in Diethylstilbestrol-Induced Squamous Metaplasia of the Developing Human Prostate," *Human Pathology*, February 1988). The authors suggest that if DES exposure in humans has resulted in similar prostate abnormalities, there could be increased rates of prostate gland inflammations and, perhaps, prostate cancer as DES sons grow older. These animal studies can only be suggestive, and require careful

follow-up among DES-exposed men.

### DES Mothers

Although no new reports focus on women given DES while pregnant, these women need to remember that they are approximately 40% more likely than non-exposed women to develop breast cancer later in life. The term "DES mother" is actually a bit misleading, since the DES-associated increase in risk applies also to the many women who took DES during a pregnancy but who never had a liveborn child; in fact, these women have an increased breast cancer risk beyond their DES exposure. Unfortunately, most of these women may be unaware of their expo-

sure, since information about DES use during pregnancy is often obtained out of concern for the health of a daughter or son.

Any woman who took DES during a pregnancy needs to be conscientious about following steps aimed at detecting breast cancer early, when treatment can be most successful. Monthly breast self-exams for all women (see article on page 5) as well as annual mammographies for those 49 years of age and over are recommended by the American Cancer Society. 



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