

## Importance of Annual Paps

By Nora Cody

YOU may have read in late June a news article that women with hysterectomies do not need routine Pap tests. The article summarized a study in the *Journal of the American Medical Association* (JAMA) showing that Pap tests were still being done on women who no longer had a cervix. The headline on the press story was dramatic: "10 Million Needless Cancer Tests."

This news was also on Internet news sites, so I sent this letter to [health@msnbc.com](mailto:health@msnbc.com)

"I am writing in regard to yesterday's articles about needless Pap tests. I was disappointed that you did not mention an important category of women who continue to need annual Pap tests due to their risk for a rare vaginal cancer"—DES daughters. These women, exposed to diethylstilbestrol in utero, are at risk for clear cell adenocarcinoma of the vagina even if their cervix and uterus have been removed, for whatever reason.

I also wish to point out that for many women, the annual or

bi-annual Pap test remains their only visit to any health care provider and offers them the opportunity to discuss other health concerns, undergo clinical breast exams, order needed blood tests, etc. This may be the reason that many doctors and nurse practitioners are reluctant to advise against annual Pap tests for women who have had hysterectomies.

Individuals seeking more information about DES and the health effects of DES exposure can go to [www.desaction.org](http://www.desaction.org) for free information."

We had more than enough validation for our concern from DES daughters who wrote on their list/serv on the Internet. Here is a posting from Debbie Ally:

"I wanted to add my 2 cents here. I did read the article and thought it was very careless on the doctor's part to say such a thing. In March of 2002 I had a total hysterectomy (uterus and cervix removed). This was due to the carcinoma in situ cells on my cervix that we just could not get rid of any other way — it was a fight that I fought for 20 years and I did think it was finally over.

But alas, on one of those "possibly unnecessary" Paps...my doctor found stage 3 VAIN (Vaginal Intraepithelial Neoplasm) that was in the scar tissue where they had sewn the vaginal canal together at the end. I was devastated to say the least

and underwent surgery (upper vaginectomy) on April 27 to remove more tissue. Basically, they cut out the previously sewn together part and are now leaving it open to allow us to discover potentially dangerous areas a lot earlier.

"The doctor was very clear that my case was a prime example of how so many women end up with terminal cancer — they simply do not see the need to have their Paps after they have a hysterectomy. They don't realize that there is a problem until they are symptomatic and by that time, it's usually well advanced.

Please never ever fail to get yourself checked and do not be swayed by stories like these. I am a 38-year-old single mom of a five-year-old little girl — what a horrible statistic I could have been if I didn't have the wonderful doctor that I have who made it clear that I needed to still be monitored!"

Another view from Wanda Robertson, who wrote:

"I actually took it upon myself to email a response to the place I read the article. I said I was disappointed they printed such an article, because people uninformed about the facts about Pap smears might take that article as gospel (and I don't mean just women in general... We all know, as DES daughters, that there are a lot of uninformed medical professionals out there!) Believe it

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# How to Join the DES Daughters Listserv

DES Daughters should check out DES-L, the DES daughters listserv and online support forum at [http://www.surrogacy.com/online\\_support/des/](http://www.surrogacy.com/online_support/des/). To join the listserv, complete the online application and get ready to share support and information with 1,000 other DES daughters! Note: this list is operated independently from DES Action.



**Yes**—I want to get answers about DES. Enclosed is my membership.

All members receive **The DES Action Voice** quarterly. Those at the \$100 level and above receive an annual report on DES Action's work and progress. All contributions are tax deductible.

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Please make checks payable to DES Action.

I am a: ☐ DES Daughter ☐ DES Son ☐ Other  
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## DES Action Affiliates and State Contacts

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Each affiliate was created and nurtured by volunteers. Write to them if you want information or would like to volunteer.

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State contacts participate in national projects organized by DES Action. Contact the national office if you would like to find out about our national projects.

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## Second Teleconference: Cancer Risks for DES Daughters

THE second CDC teleconference focussed on other cancer risks for DES daughters. The presenters were Elizabeth Hatch, PhD, and Candy Tedeschi, RN, OGNP. Dr. Hatch is an assistant professor at the Department of Epidemiology at the Boston University School of Public Health. She conducted cancer research for nine years at the National Cancer Institute, where she was the co-principal investigator of the follow-up study of DES-exposed cohorts. Candy Tedeschi coordinated the DES Screening Center for three Long Island, New York counties for 20 years. Candy continues to care for DES daughters today.

Dr. Hatch spoke first about the general results of their survey comparing DES daughters with non-exposed women. She stated: "We found that overall, the rate of all types of cancers combined was approximately the same as that expected in the general population... The only cancer which was significantly elevated in risk at the end of that first follow-up was CCA (clear-cell adenocarcinoma), which was already known to be strongly linked to DES. There were three cases among the exposed and none in the unexposed, which corresponded to a 40-fold relative risk of CCA among the DES-exposed....

"The only cancer type that occurred in more than a

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**We found that overall, the rate of all types of cancers combined was approximately the same as that expected in the general population... The only cancer which was significantly elevated in risk at the end of that first follow-up was CCA (clear-cell adenocarcinoma), which was already known to be strongly linked to DES.**

handful of women in the first study was breast cancer, and even breast cancer was quite rare in our study. This is because in general, cancer is rare among younger people, and women who are exposed to DES are just beginning now to enter the age groups when breast and other cancers become more common...

"In addition to concerns about CCA and breast cancer, there has been an ongoing concern about whether the more common type of cervical cancer, squamous cell cancer... may be increased among the DES exposed...early (cellular) changes are commonly referred to as cervical dysplasia and they may eventually progress to cancer if not treated...

"We now know that the primary cause of cervical dysplasia in cervical cancer is infection with human papilloma virus, or HPV. HPV is a

very common sexually transmitted infection.... Other risk factors, such as smoking, dietary factors, oral contraceptive use and perhaps DES exposure may predispose women with HPV to be more susceptible to carcinogenic changes.

"We...found a two-fold higher risk of high-grade cervical dysplasia among the DES-exposed...we found that the earlier a woman was exposed during gestation, the higher the risk of cervical dysplasia. Women exposed very early, at seven weeks post-conception or before, had 2.8 times the risk compared to unexposed women, whereas those exposed at 15 weeks or later only had a 1.4-fold increased risk, which was not statistically significant...

"If this is a true causal association, there are a couple of theories about why DES-exposed women might be at higher risk. The first is that DES causes structural changes in the cervix, which may make it more susceptible to infection with HPV. The second theory is that perhaps DES-exposed women might have some immune system changes that result in their being less able to fight off HPV infection."

Candy Tedeschi spoke in detail about the recommended annual exam for DES daughters. For a copy of the recommended exam, contact our office. ■



# Q&A On Reproductive Risks for DES Daughters: From the First Teleconference

*Arthur Haney MD, Dept. of Ob/Gyn, University of Chicago Medical Center, and Candy Tedeschi, NP, were the experts from this CDC teleconference. Here are some of the most frequently asked questions, answered by Dr. Haney.*

**Q** I am a DES daughter, with a lot of visible DES damage, and I've had lots of infertility problems and cancers as well. I just am wondering, has anyone ever considered the question, the more visible and extensive the damage from DES, such as the malformed cervix, the T-shaped uterus, the blocked fallopian tubes, etc., the more the damage, the greater the likelihood of infertility problem, and, perhaps, even reproductive cancers?

**A** I think it would be very logical to assume, and let me just say it's all temporally related to when your mother took the drug, so if the drug was given precisely at the time the Mullerian duct system was developing, you can expect a more complete effect when the vagina, cervix, uterus and fallopian tubes formed. It's not precisely at the same time, so depending on when she took the drug, you may see some variation from patient to patient and how much effect.

I think if you really were unfortunate and you have effects in all those sites, it is very likely, although logical but unproven, that you're going to have a greater

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**Doctors are saying that my reproductive tract looks absolutely normal. Will I still be at a higher incidence of ectopic pregnancy, pre-term labor, or miscarriage?**

probability of reproductive problems.

**Q** I was trying to get pregnant with my first child and we're having some difficulty. It's been about 8 months. My question is, visually and from some tests, the doctors are saying that my reproductive tract looks absolutely normal. Will I still be at a higher incidence of ectopic pregnancy, pre-term labor, or miscarriage?

**A** Luckily, that information is known. Dr. Kaufman, when he did a study about DES upper tract effects, divided the patients into those that were not exposed, those that were exposed and had the deformity, and those that were exposed, but didn't have the deformity. The deformity itself was again temporally related in the severity, both dose and time.

What he found was that the group that was unexposed had a baseline risk of problems. The group that had the exposure and clear anatomic deformities had a higher rate of ectopic pre-term labor, incompetent cervix, etc. And those that were clearly ex-

posed, but didn't have an anatomic defect, were in-between. I would typically say that your risk of a miscarriage, pre-term labor, and ectopic is high enough to say you should be treated as if you were at risk, but it's going to be less than the people who have the deformity.

What it means to you is that when you get pregnant, which hopefully you'll do shortly, they do an ultrasound exam at six and a half to seven weeks from the time of the last period to be sure it's in the uterus and not in the fallopian tube, and that your doctor examines you frequently throughout the end of the first trimester into the second to be sure that the cervix stays its normal length, and then treat you as if you're someone who has had pre-term labor in the past. Those are really precautionary, but as Dr. Kaufman's data does suggest, if you're anatomically normal but know you're exposed, you're somewhat intermediate in risk.

**Q** I've had several female problems. I had endometriosis so badly that I had to have a hysterectomy at 31 years old. I was able to have one child, I have a daughter. I had four months of premature labor, bed rest, and I do know that I am a DES daughter. Could the endometriosis be caused from DES? I know that I had cervical abnormalities and now I have had a complete hysterectomy....

**A** The data as exists, Dr. Stillman in Washington, DC, looked for that specific question – was the frequency of endometriosis, which again is very common, but was the frequency higher? He found...it did appear that the frequency of endometriosis is higher.

Endometriosis typically is that the cervical canal is narrow and it's harder to expel the menstrual debris, and some of it regurgitates out the fallopian tube, attaches, and then we call it endometriosis when we see it in the abdominal cavity. The cervical canal in DES exposed women is narrower and so that made perfect sense.

The patients who are at the greatest risk, I think, are not just women who had had DES exposure, that probably increases the risk somewhat, but those that have had a conization, had some surgical procedure done to the cervix because of a dysplasia, the incidence of a very narrow stenotic cervix and hence endometriosis in that population is very high.

I think it's probably true and they may well be related, although the background incidence of endometriosis is also very high. In any individual patient I couldn't tell you whether you were destined to get it anyway or it's related to DES, but overall I think you're exactly right: it's a higher frequency in DES-exposed women.

**Q** I have a T-shaped uterus and I've been exposed to DES. With that I have a higher risk for miscarriage and pre-terms labor, and then with the T-shaped uterus, I obviously have a higher risk for those things. We're in the process of insemination now. We've tried one cycle, but it hasn't worked so we're in our second cycle now. Looking forward, thinking about possibly moving on into IVF, what would my probability be of success with IVF, and then how much would I want them to put back in me?

**A** That's a hard one to judge. Hopefully, you won't get to the point of needing IVF, but if you do, I think the data would suggest that your likelihood of conception...is slightly lower. It's not dramatically lower, but lower. The flip side is, if I try to compensate by putting more embryos back, if you had a set of triplets your likelihood of delivering them far enough to get viability would be less than a person not exposed.

On that score, I wouldn't argue that you should get any more embryos than a non-exposed patient. To try to

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**I have a T-shaped uterus and I've been exposed to DES...what would my probability be of success with IVF?**

compensate for the slightly lower pregnancy rate and then get a multiple gestation, even twinning, and have a less likelihood of walking away with living children, I don't think it's a good bargain.

**Q** I had a fibroid removed from my cervix in May. I have a history of structural deformities. I have a coxcomb cervix...and a ring of tissue that sorts of narrows the vagina, which has been a huge problem. I didn't know about the risks of cervical surgery before I had my myomectomy. I do have scar tissue and I'm just wondering if anything can be done. I'm extremely tender. I can't even withstand an ultrasound, and that's been going on since the surgery in May. I just don't want to live with that for the rest of my life.

**A** Fibroids can occur as cervical fibroids, but that's fairly unusual. If it was truly of the cervix and there is a deformity, then in cutting out the fibroid they actually altered the upper vagina and cervix, then you may well have what you're experiencing as a change in symptoms. I don't want to go too much further because I'd almost have to know the details of the surgery, because that's a very large fibroid to take out from the cervix. They really make you bleed and uncomfortable. You may well be having scarring because of the surgery. ■

## CDC's DES Update Campaign Wins More Awards

CDC's DES Update Campaign was honored this year with two ASTRID awards and one Mercury award. These awards are given out by MerComm Inc. MerComm was founded in 1987 for the purpose of advancing the arts and sciences of communications in an international arena. It strives to establish and promote high standards of individual and collective achievement. Two of the awards they give out are the ASTRID and the

Mercury awards.

The ASTRID Award "serves as a showcase for excellence in design" and was founded in 1991. It is given in an International Competition Honoring Outstanding Achievement in Design Communications. The ASTRID awards are one of the largest awards in the world. The Mercury Award is given in an International Competition honoring Outstanding Achievement in

Professional Communications.

CDC's DES Update won the 2004 Bronze ASTRID award for the Health Care Provider CD-ROM and Honors for the Consumer Binder. CDC's DES Update won the Honors Mercury Award in the Public Health Awareness Campaign Category.

We would like to acknowledge all of our partners who were instrumental in the development of the health education campaign. ■

## NCI DES Steering Committee Update

By Kari Christianson

ON May 13 I attended the most recent meeting of the DES Steering Committee, which oversees long-term DES research conducted through the National Cancer Institute. I serve as DES Action's representative to this group.

These meetings include the principal investigators (who are medical researchers, epidemiologists and statisticians) and consumer representatives, including a representative from DES Action. They are held twice a year, once in Bethesda, Maryland, and once by teleconference.

The principal investigators (study leaders) provided updates on the status of reporting data from the most recent questionnaires sent to DES cohort participants. Questionnaires are now sent to cohort participants once every five years. Since we are now in the middle of collecting

data from the questionnaires and there is nothing to report yet, the meeting focussed on ways to improve data collection and interesting avenues of research to pursue.

During this recent meeting, the phrase "panning for gold" was used as the committee discussed the development of the next questionnaires two years from now. The group talked about the need for questions which draw out, but do not suggest, personal medical information.

The response rate of the DES cohort participants continues to be very high at over 90%, but with each succeeding questionnaire cycle participants are lost due to address or name changes. Follow up systems to combat attrition have been and continue to be developed.

Within our DES consumer community there is considerable

interest in offering to replace anyone who is "lost." The validity of information in this research is based on the long-term continuation of the participants in the cohorts, as well as verification of DES exposure. The cohorts of DES mothers, daughter, sons and matched controls were invited to be participants as many as thirty years ago. The newer cohort of third generation participants was invited from the existing, older cohorts. Therefore, no new participants are able to join these existing cohorts.

The exacting, deliberate, and essential investigation into the long term effects of DES exposure will continue only if we, the consumer community of DES Action, continue our efforts to advocate for funding of this necessary research. Stay tuned for more news on this front from DES Action. ■



# Study Shows Chemical and Drug Interaction with Estrogen Can Be Dangerous

By Pat Cody

AN industrial solvent in the environment and an often prescribed drug (Depakote) have been found by researchers at Duke Comprehensive Cancer Center to increase estrogen and progestin activity inside cells. This means, according to a new study directed by pharmacologists at Duke University headed by

Donald McDonnell, that they could trigger reproductive failures, and possibly even breast cancer, in women exposed to these chemicals.

A press release from DukeMedNews gives this explanation:

"Our study demonstrates that these chemicals boost the activity of estrogens and progestins inside cells 8 to 10 fold," said McDonnell. "These data should prompt caution for patients who are exposed to either of these chemical compounds while taking any estrogen or progesterone-containing medications, such as hormone therapy, oral contraceptives, or tamoxifen for breast cancer."

The release went on to identify the chemicals: ethylene glycol methyl ether (EGME), found in varnishes, paints, dyes, fuel additives and the semi-conductor industry. The drug Depakote is among the top 100 drugs prescribed in the US, and is used to treat bipolar disorder, seizures and migraines.

"Exposure to this class of compounds is known to induce reproductive toxicity in people and rodents. In men, they cause reduced sperm counts and in women they cause spontaneous abortion and irregular ovulation...McDonnell's team...found that both compounds accelerate the process called gene transcription – the 'reading' of the cell's genes to build the cell's machinery. Transcription is required for cells to thrive and carry out their intended purpose.... Yet uncontrolled or inhibited transcription can result in any number of diseases and dysfunctions, including cancer."

Dr. McDonnell said that these findings "should raise awareness in the scientific and medical community about the importance of developing screening technologies to analyze various chemicals of the mechanistic class for their activity on hormones...and alert the public to the potential for such drug-drug interactions." ■

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or not, someone signing him (or her!) self "bored med student" replied and said, 'if you've had a hysterectomy and don't have a cervix any more, it's impossible to do a Pap smear. You only need visual inspections done and colposcopies if needed.' Obviously this person is going to graduate and be one of the aforementioned uninformed medical 'professionals.' Visual inspections aren't going to reveal any cellular precancerous or cancerous changes! SO frustrating!"

This posting led to a reply from Patsy:

"I have had vaginal Paps done many times! Unfortunately mine are abnormal most of the time. I had a hysterectomy several years ago and I too thought I would not have to have Paps anymore. Lucky for me my GP insisted and did one. I have had VAIN II or III with possible high grade lesion and had treatment for the precancerous cells. Whenever I went to the gyn oncologist it seems like he had a new intern working with him every time. At least they got educated about it!" ■

## DES ACTION TRIBUTE PROGRAM

We'd like to offer a great idea for that person who has everything: the DES Action Tribute Program. Our Tribute Program is a way for you to make your contribution in someone's honor or memory. Holiday gifts, birthdays, anniversaries, or memorial remembrances—all are appropriate occasions for a Tribute gift.

When you send your Tribute gift to DES Action, simply enclose a note indicating in whose honor and for what occasion the gift is given. Make sure to include the honoree's name and address as well as your own. We send an acknowledgment letter to you and to the honoree. The amount of the gift is not mentioned.

# Book Note

By Pat Cody

Many of our readers have written us about auto-immune conditions, which is why this listing of a new book caught my eye in the 28 June issue of *Publishers Weekly*. It lists a new book, *Women and Autoimmune Disease: the Mysterious Ways Your Body Betrays Itself*, written by Robert G. Lahita MD and Ina Yalof and to be published by Regan Books on 20 August.

The reviewer describes the work in this way:

"Lahita, aided by medical writer Yalof, draws on research and case studies to identify 16

conditions that have been categorized as autoimmune diseases (he includes chronic fatigue syndrome, though its cause remains uncertain) and describes at length the symptoms, causes and possible treatments for this debilitating ailment. Treatment is complicated...since patients are often diagnosed too late because their complex symptoms mimic those of other conditions....This clearly written text should be extremely useful to people with this difficult ailment, their families and caregivers. Lahita, however, is suspicious of alternative herbal or homeopathic therapies, which he says have not

been scientifically found to be effective."

We hope our readers who suffer from autoimmune diseases find this book helpful. ■

We always need the names of physicians who are informed about DES and sensitive to the needs of their patients. If you have such a referral, let us know!

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