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New Assessment of Cancer Risk for DES Daughters

“Cancer risk in women prenatally exposed to diethylstilbestrol,” Rebecca Troisi, et al, *International Journal of Cancer*, Volume 121, No. 2, July 2007.

Reviewed by Kari Christianson

DES Daughters who follow research findings know of their increased risk for clear cell adenocarcinoma of the vagina and cervix, as well as their increased risk for breast cancer after age 40. The nagging concern is whether they are at risk for other cancers, particularly those of the reproductive system.

“... the incidence rate for total cancers among DES-exposed women is comparable to the expected rate for the general population”

This research article is an update of previous studies of the risk for cancer among DES Daughters. With the response data through 2001 from the National Cancer Institute DES Combined Cohort Follow-up Study, lead author Rebecca Troisi, Sc.D., of the Division of Cancer Epidemiology and Genetics at NCI and Dartmouth Medical School, reports that “. . . the incidence rate for total cancers among DES-exposed women is comparable to the expected rate for the general population”

This study confirms that the risk for developing clear cell adenocarcinoma remains for DES-exposed women through their reproductive years, although at a lower rate than the peak age of about 25. Troisi states, “. . . the risk appears to be elevated through at least age 39 indicating the need for continued surveillance to assess the impact of this exposure when the population reaches the usual age

range for this rare tumor,” which is after menopause.

Troisi continues, “Removing breast cancer and CCA from our current analysis revealed about a 20% excess for all other cancers combined among DES-exposed women compared with unexposed women, though the estimate was not statistically significant and the CI (confidence interval) wide.

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Sex of Children Born to DES Daughters Is of Interest to Researchers

Dose and Timing are Critical

“Secondary Sex Ratio among Women Exposed to Diethylstilbestrol *in Utero*,” Lauren Wise, et al, *Environmental Health Perspectives*, Vol. 115, No. 9, September 2007.

Reviewed by Kari Christianson

Does *in utero* DES exposure have anything to do with the ratio of male to female births for a DES Daughter?

To answer this question about secondary sex ratio — which is the proportion of male births compared with female births — Lauren A. Wise, Sc.D., of Slone Epidemiology Center at Boston University, and the team of researchers with the National Cancer Institute DES Combined Cohort Follow-up Study analyzed data provided by DES Daughter participants. This is the

first reported study to evaluate secondary sex ratio in women exposed *in utero* to diethylstilbestrol.

DES has long been recognized as a potent endocrine disruptor. Previous studies have suggested that “exposure to endocrine disrupting compounds can influence infant sex ratio. It is hypothesized that endocrine disruptors, such as DES, could affect secondary sex ratio through changes in hormonal concentrations around the time of conception or through changes in the quality of cervical mucus before ovulation. . . .”

Many factors were weighed in the data collected about the pregnancies of the DES Daughter cohort participants. According to Wise, “We considered maternal age, cigarette smoking, calendar year of

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Want to be in touch, via e-mail, with other DES Daughters? As a benefit of being a DES Action member you can join the DES Action Daughters On Line Support Group. That way you can ask questions and share experiences common only to those of us who are DES exposed.

To join the DES Action On Line Support Group simply send a blank e-mail to:
DESactionDaughters-subscribe@yahoogroups.com

You'll receive an e-mail back from Yahoo! Groups confirming your request to join. It offers two registration options and the easiest is Option 2. Click "Reply" so the note is sent back.

Once we've checked to be sure you are a current DES Action member, you'll receive a welcome to the group letter explaining how to send messages. Then you can participate in the e-mail conversations, or just quietly read and enjoy the learning experience.

MISSION STATEMENT

The mission of DES Action USA is to identify, educate, support and advocate for DES-exposed individuals as well as educate health care professionals.



Published quarterly by:

DES Action USA
158 South Stanwood Road
Columbus, OH 43209
ISSN 1522-0389

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Assessment of Cancer Risk *from page 1*

Nonsignificant excess RRs (rate ratios) were noted for thyroid cancer, lymphomas and brain and lung malignancies, while deficits were observed for colorectal cancer and leukemia. The data do not support an association of DES with carcinoid tumors, a hypothesis that was based on anecdotal reports.” Carcinoid tumors are rare cancer-like tumors that originate in the digestive tract or lungs; these tumors tend to grow or spread slowly.

While a 20% excess rate for cancers seems high, it is not considered so by researchers because of the vast number of available cancers. Scientists will watch cancer rates for those with the higher rate ratios listed above, but for now, no specific DES link can be made to them.

Multiple factors were considered in this detailed analysis of cancer risks, including family history of cancer, education, body mass index, smoking, alcohol use, and menopause. Additionally, the “risk of total cancer (with and without breast and CCA) was not associated with DES dose or gestational age at DES exposure.”

Of note is that this analysis of the 2001 data did not find an association between DES exposure and an increased risk for endometrial or ovarian cancer.

Given the relatively young age of the cohort participants in this survey, Troisi recommends continued scientific follow-up to determine whether there will be a higher risk for any other cancers among DES Daughters.

But, she states, “At this point in follow-up, there is no convincing evidence of any other excess risks except for these two sites (*ed. - breast and CCA*).” Data collected from the 2006 NCI DES Follow-up Study questionnaires is now being reviewed, and work is underway to tabulate results, but it takes time.

The complexity of the data may give us pause, but the need for continued research to understand potential cancer risks for DES Daughters is clear. Until additional information is available to help identify *if* other cancer risks exist, there are proactive steps we can take, such as never missing a yearly DES gynecological exam. Also, keep track of and report any health changes to your physician. **DES VOICE**

Sex of Children *from page 1*

child’s birth, parity (i.e., birth order), and the use of fertility drugs as potential confounders.”

Additionally, because DES exposure causes fertility problems for DES Daughters, multiple statistical analyses, including a separate analysis with first-borns only, were used to lessen any bias toward DES Daughters who were able to give birth multiple times. The data of each cohort in the NCI DES Follow-up Study also were analyzed separately to confirm dose and timing results.

Wise reports, “Although we found no overall association between *in utero* DES exposure and secondary sex ratio, DES-exposed women who were first exposed earlier in gestation and to higher doses gave birth to a significantly higher proportion of males. . . . These findings are the first to suggest a link between *in utero* DES exposure among women and the sex ratio of their offspring, and require replication in other studies with data on dose and timing.”

What do these findings mean for the DES-exposed community? This study may represent yet another example of

how data from DES Daughters are able to help researchers better understand the effect of endocrine disrupting compounds on human reproduction. And it gives us a better understanding of individual reproductive outcome differences based on gestational timing of exposure and the total DES dosage that a DES Mother received. **DES VOICE**

“These findings are the first to suggest a link between *in utero* DES exposure among women and the sex ratio of their offspring.”

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REFLECTIONS ON A DRUG COMPANY LAWSUIT

By Kim Mazeres

I had been in the jury pool for the majority of the summer. Had phoned in several times only to be told not to appear. Had filled out a 20-page pre-trial juror questionnaire for a construction defect case, only to have it continued. So, when I received another 20-page questionnaire in late August for a different case, I thought, “here we go again.”

As I worked my way through the questionnaire, it became obvious the case was about pharmaceuticals. I flipped quickly back to the front pages that I had not read, only to have my jaw hit the floor. The case was against Upjohn and Wyeth for their distribution of hormone-replacement drugs, Prempro and Premarin. Three plaintiffs were claiming that these pharmaceutical companies had known their drugs caused breast cancer, yet kept distributing them – an eerily familiar complaint for us DES Daughters.

Filling out the last few pages of that questionnaire was sure cathartic for me. Answering questions such as:

“Who do you trust to give you the most accurate information about prescription drugs?

- a) the FDA;
- b) pharmaceutical companies; or
- c) your medical provider.”

Hey, I thought, what happened to d) NONE OF THE ABOVE? And, that’s exactly what I wrote on the

questionnaire, and told them WHY, as a DES Daughter, I didn’t trust anyone when it came to telling me the truth about prescription drugs. I thought, “If these drug company attorneys are going to read this, I’m gonna let them have it with both barrels.” So, imagine my surprise when I was still called to serve on the jury!

Driving to the courthouse the morning of Tuesday, September 11th, my emotions ran the gamut —

- “I can’t believe these damn drug companies are still as greedy as they were in 1960 when they pushed DES to my mom’s doctor,”
- “Hmm . . . maybe they’ll seat me on this jury anyway,”
- “I’m not going to be able to sit in that courtroom for a month and listen to the drug companies’ line of bull.”

Not surprisingly, I was told immediately upon check-in at the courthouse that my services wouldn’t be required. Clearly, what I’d said on the questionnaire had an impact. Attorneys for the defense used their exclusionary powers to keep me off the jury. It was gratifying to know the drug company lawyers actually had read what I wrote on the questionnaire. And I was still darned excited that this case was to be heard in my hometown of Reno, Nevada.

I had almost forgotten about the case, when a “Breaking News” e-mail hit my work in-box on Wednesday, October 10th. The headline screamed, “Jury Orders Wyeth to Pay Out Millions.” I whooped with joy in my office, thinking, “Yes, the jury wasn’t duped by Wyeth, or its attorneys!” (Upjohn had settled with the plaintiffs for an undisclosed amount prior to the case going to court).

The three Nevada women have been awarded \$35 million in compensatory damages and \$99 million in punitive damages against Wyeth, who is fighting more than 5,000 of these types of lawsuits nationwide.

The Nevada jury found the pharmaceutical giant was negligent, produced a defective product and concealed facts about the safety of its drug. And, while Wyeth will appeal this ruling, the moral satisfaction alone for these three women makes me grin.

A victory against drug giants . . . we’ve taken another small step in holding these companies accountable for their actions. Maybe, just maybe, now they’ll think twice about promoting drugs their research has shown as harmful. And, one thing there is no “maybe” about — how proud I am that my hometown jury held Wyeth responsible.

Meantime, DES Action continues the fight. The fight to ensure all DES Sons and Daughters are informed about diethylstilbestrol. The fight to ensure research about ongoing effects of this drug continues. The fight to ensure education about the impact of DES is accessed by every doctor. And, last but definitely not least, the fight to hold greedy drug companies accountable for a drug they heavily promoted even though they knew it didn’t work and could cause harm. At least in this case, it was a good day in court.

Kim Mazeres is a DES Daughter and a Board member for DES Action. She was born in Santa Rosa, California in 1961, and has resided in Reno, Nevada for the past 25 years.

DES VOICE

YOUR VOICE

The following article, by DES Action member Joyce Solomon, is another in a recurring series of personal stories to be published in the VOICE. We hope you enjoy reading about the spirit of our members who are living good lives in spite of, and with, DES exposure. Do you have a DES story that communicates hope? Please e-mail Board Member Ann Giblin, Ann@WinterlakeAssoc.com, for more information.

Poolside Advocacy

We were at the swimming pool, my neighbor and I, for the adult early swim. In the pool we tended to challenge each other by pushing ourselves in the lap-lanes. But today we took time to visit. I was startled by a woman standing near me who asked the pointed question, “Did you go on to have other kids?”

I looked up but didn’t recognize her, although I had noticed her and her daughter swimming happily together in the pool some moments earlier. The woman’s question was in response to the conversation she had overheard.

My neighbor had recalled how small my daughter was at birth. At two months premature she weighed three pounds, thirteen ounces. Now seventeen, she is petite but otherwise shows no outward signs of being a preemie. I can more comfortably reminisce about her birth these days, though at the time her prematurity was quite traumatic.

“Was there a reason she was premature?” my neighbor asked, which was what sparked the interest of the other woman who had walked closer to us, quite eager to join our conversation.

This was a question I had

faced many times; I always hesitate a bit to assess the context and person asking. How much to tell, how much do questioners want to know or how much can they, or do they want to comprehend? I made my decision, took a deep breath and decided to dive right in.

“Yes, indeed,” I answered. “There was a reason my daughter was premature. My mother, along with many other mothers, had been prescribed the drug, DES, an estrogen given to pregnant women from the 1940s to the 1970s. It was supposed to prevent miscarriage, but we now know it didn’t work.”

“What it did,” I continued, “was cause a range of health problems for the children born from those pregnancies. They include reproductive abnormalities, infertility, cancers and in my case difficulties in carrying a baby to term.”

I gave them a brief sketch of my reproductive health history, recounting that I’d had three pregnancies ending in miscarriage, and one more severely premature daughter who didn’t make it either. I shared what it is like to live with this pain that sometimes diminishes, but never

disappears . . . to always think of them as my children, too.

As I continued, watching indignation grow, I recounted to these moms how I, and others, have to live with statutes of limitation on lawsuits against the drug companies who profited from DES and the paltry “discovery” limits. How most of us have no chance at legal recourse or compensation, even though, as in my case, I possess the packing slips my mother had saved that clearly specify DES from Eli Lilly.

It was time to go. I wound up the conversation, needing to get dressed and get my daughter for carpool. As I said goodbye to the other moms, I was reminded once again of how important and validating it was for me to take that deep breath, to go ahead — even poolside in a swimsuit — to tell my DES story. It seems like I cannot win a lawsuit, but I can encourage others to find out if they were exposed to DES, or more simply, to actively participate in their healthcare decisions.

“Yes,” I told them with a smile as I waved goodbye, “I have three living children, my daughter and two others — as well as those I hold dear in my heart.” **DES VOICE**

DES Daughters Need Yearly Pap/Pelvic Exams

But You May Have To Tell Your Doctor

By Fran Howell

All women should have annual pelvic exams, but not all women need annual Pap tests. This is what your doctor is being told by respected organizations such as the American Cancer Society and the American College of Obstetricians and Gynecologists. But the devil is in the details and both organizations say in their *fine print* that **DES Daughters need yearly Paps** even if other women don't. The trouble is too many doctors are failing to read the fine print.

By way of explanation, a pelvic exam, which involves stirrups and a speculum, allows your health care provider to view your cervix to look for abnormal cell development. According to University of Pennsylvania Student Affairs Health Services, other parts of a total well-woman exam include palpation (pressing with fingertips) around the vagina, a rectal exam and a clinical breast exam.

Then, if warranted (and it is every year for DES Daughters), a Pap test can be done as part of a pelvic exam. That involves scraping cervical cells (and in the case of a properly done DES Daughter Pap, scraping vaginal cells as well).

From a patient's perspective it all seems to be one exam. But when speaking with health care providers, it is important for DES Daughters to specify that they want an Annual Pelvic Exam complete with a proper DES Pap Screening.

In recent years cervical cancer screening guidelines are calling for skipping a year or two between Pap tests for some unexposed women. That's because the HPV virus causes most cervical cancers. Therefore, mature women in monogamous relationships are at diminished risk for this sexually transmitted disease.

However, DES Daughters have a


lifelong risk for a different kind of cancer, one linked to DES exposure: clear cell adenocarcinoma (CCA) of the vagina and cervix. To check specifically for it, they need annual pelvic exams complete with a Pap test.

This also holds true for DES Daughters who've had a **hysterectomy**. They require a yearly Pap screening as well. Even though the cervix was removed in the surgery, they remain at risk for CCA of the vagina and must be screened for it.

Unfortunately, most doctors are under the misconception that for DES Daughters there is no CCA risk after age 30. But DES Daughters in

their 40s and 50s have been diagnosed with CCA. The numbers are small, but they do exist. At this time there is no known upper age limit for the development of CCA.

So DES Daughters often find themselves in the uncomfortable position of having to strongly advocate for annual Pap screenings because their doctors failed to read fine print in revised cervical cancer cytology guidelines.

To ensure you get the proper DES Pap/pelvic exam, clip out the directions on the following page and bring them to your doctor when you go in for your annual screening. 

DES VOICE

No Significant Loss of Fertility for DES Sons, Nor Gender Difference in Their Offspring

"Time to Pregnancy and Secondary Sex Ratio in Men Exposed Prenatally to Diethylstilbestrol," Lauren A. Wise, et al, *American Journal of Epidemiology*, Vol. 166, No. 7, October 1, 2007.

Reviewed by Fran Howell


There have been conflicting research results through the years as to whether DES Sons have higher infertility rates than unexposed males. Results from this new study show exposure does not adversely affect fertility rates for DES Sons, nor does DES appear to affect the gender of their offspring.

Researcher Lauren A. Wise, Sc.D., with the Slone Epidemiology Center at Boston University used responses provided to the National Cancer Institute DES Follow-up Study to compare 1,246 DES Sons

with 1,250 unexposed men of similar age and health habits.

She and her team examined what's called "time to pregnancy" — the number of menstrual cycles (or months) from the time a couple stops contraception until a pregnancy is achieved. According to Wise, this is considered a sensitive indicator of fertility for a couple.

The study found that DES Sons were able to father children at similar rates to those for unexposed men. In addition, while DES-exposed men fathered more girls than boys, unexposed men fathered more boys. But it was statistically a dead heat, with the difference being very slight.

Meanwhile, the other sex ratio research, reported in this *Voice*, shows DES Daughters in a similar study gave birth to more boys than girls, so it is impossible to jump to any major conclusions at this point. 



Department of Health and Human Services

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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

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BOOK NOTES

HOOKED

Ethics, the Medical Profession, and the Pharmaceutical Industry

Howard Brody • Rowman and Littlefield, 2007, 367 pp., \$29.95.

By Pat Cody

Dr. Brody explains his title by writing that “Medicine is ‘hooked’ in two ways. In one sense, medicine’s relation to the pharmaceutical industry, and the gifts and rewards that it dispenses, has been likened to an addiction....Yet medicine and the pharmaceutical industry are also ‘hooked’ in quite a different way. Remove the industry and its products, and a considerable portion of scientific medicine’s power to help the patient vanishes.”

He knows whereof he speaks. Howard Brody directs the Institute for the Medical Humanities at the University of Texas-Galveston and earlier di-

rected the Center for Ethics and Humanities in the Life Sciences at the University of Michigan. He has a lifelong commitment to public health and to emphasizing the importance of ethical considerations in medical care. He points out that “The idea of being a professional includes among other features that one is supposed to act in a trustworthy way.... Medicine has for many decades now been betraying this public trust in the way that it has accepted various benefits from the pharmaceutical industry.”

In the final section he writes about possible solutions: changes in physician behavior, laws and regulations, divestment strategy. In an epilogue Dr.

Brody gives these thoughts:

“We do need to do something. ‘We’ in part is the medical profession, which must shoulder the burden of taking back its system of education from commercial influence, and breaking its longstanding addiction to drug company largesse of all forms. ‘We’ is also the American taxpayer, who must accept the fact that if we want scientific, unbiased research and safe drugs, we cannot expect a for-profit industry to foot the bill for us and allow us to enjoy one tax cut after another. We will have to accept the need to fund a major investment in pharmaceutical research and drug safety monitoring, to be sure that it is done in the public interest.”