DES Action VOICE

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A FOCUS ON DIETHYLSTILBESTROL

FALL 2006 #110

DES Daughters At Increased Breast Cancer Risk After Age 40

"Prenatal Diethylstilbestrol Exposure and Risk of Breast Cancer," by Julie R. Palmer, et al, Cancer Epidemiology Biomarkers and Prevention, August 2006.

Reviewed by Fran Howell

A new group of women has been identified as having an increased risk for breast cancer. Using information collected by the on-going National Cancer Institute DES Follow-up Study, researcher Julie Palmer found that DES Daughters are nearly two times more likely to develop breast cancer, after age 40, than unexposed women. Palmer is at Boston University's Slone Epidemiology Center and is a Principal Investigator with the NCI DES Follow-up Study.

She and her team compared exposed and unexposed participants, taking into account the number of births and the age at first birth, among other factors related to breast cancer risk. The analysis included 4,817 exposed and 2,073 unexposed women, and, to date, 102 cases of invasive breast cancer have occurred in the combined group.

According to Palmer, "the finding that DES Daughters are 1.9 times as likely to get breast cancer once they hit age 40, compared with unexposed women, confirms the hypothesis that prenatal hormone levels influence breast cancer risks."

She adds that for DES Daughters over age 50, the estimated relative risk was even higher, but the smaller number of study cases in this older age group means additional research is needed to confirm the finding. She says, "knowing what we do about the heightened breast cancer risk for DES Daughters over age 40, I urge them to pay attention to this new information."

"What we are telling DES Daughters is that they should get annual breast screenings after the age of 40," says DES Action Program Director Kari Christianson. She points out that the American Cancer Society makes the same recommendation for all women. However, she adds, "DES Daughters should remain extra vigilant. That means having your health care provider do a clinical breast exam when you go in for your yearly gynecological screening, having an annual mammogram, and doing routine

> The highest relative risk of developing breast cancer was observed in study participants from groups with the highest cumulative doses of DES exposure.

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DES Daughters May Experience Slightly Earlier Menopause

"Age at Natural Menopause in Women Exposed to Diethylstilbestrol in Utero," Elizabeth E. Hatch, et al, American Journal of Epidemiology, 1 October 2006; 164: 682-688.

Reviewed by Kari Christianson

It may not seem all that important to individual DES Daughters, but in the world of research the finding is significant. "The average age at menopause was 52.2 years in unexposed women and 51.5 years in DES-exposed women."

While the span in age may seem minimal at first glance, it reflects a statistical difference apparently caused by DES exposure alone. According to researcher Elizabeth Hatch, other known reasons for early menopause, such as smoking, birth control and HRT use, pregnancy history, and age of mother's menopause were reviewed without changing the overall results.

Data was collected from questionnaires filled out by participants in the National Cancer Institute (NCI) long-running DES Follow-up Study. Hatch is at the Boston University School of Public Health and is a Principal Investigator with the NCI DES Follow-up Study.

It shows that DES Daughters are 50% more likely to experience natural menopause at any

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DES Action

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Columbus, OH 43209

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Join On Line Support Groups for DES Daughters or Sons

Want to be in touch, via e-mail, with other DES-exposed individuals? As a benefit of being a DES Action member you can join either the DES Action Daughters On Line Support Group, or the one for Sons. 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

To join the DES Action Sons On Line Support Group simply send a blank e-mail to: DESactionSons-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.

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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.

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Increased Breast Cancer Risk *from page 1*

breast self-exams."

According to Christianson, "for many years DES Daughters were focused primarily on their increased risk for vaginal and cervical cancer. Now they must pay attention to their breast cancer risk as well."

News of this study doesn't surprise DES Daughter (and DES Action member) Deborah Wingard. At age 39 she was diagnosed with breast cancer.

Wingard discovered a lump in her breast not long after having a clear mammogram, so she's a strong advocate of breast self-exams. Ten years later another diagnosis of cancer meant a second mastectomy. Wingard urges all DES Daughters to pay serious attention to this breast cancer risk.

According to researcher Palmer, "this is really unwelcome news because many DES Daughters are just now approaching the age at which breast cancer becomes more common."

Her study suggests that DES-exposed women are developing the typical range of breast cancers, after age 40, at a faster rate than unexposed women of the same ages. Palmer says the research team also found the highest relative risk of developing breast cancer was observed in study participants from groups with the highest cumulative doses of DES exposure.

When asked about HRT use by DES Daughters, Palmer says it might be wise for exposed women to avoid these extra hormones, if possible. "Use of hormone supplements is, in itself, an independent breast cancer risk factor, so DES Daughters may choose not to compound their already increased risk."

Although researchers do not completely understand the DES connection to breast cancer, Palmer says some scientists believe the excess estrogen increased the number of breast tissue stem cells available at birth - cells which could malignantly transform into cancer.

So if it is true that excess estrogen, in utero, impacts breast cancer risk later in life, "other environmental factors that increase fetal exposure to estrogenic compounds may do the same thing," Palmer says. "Our study suggests that such environmental exposures may deserve more serious consideration." DES VOICE

Earlier Menopause *from page 1*

given age. For example, that means if there are *two* unexposed women who reach menopause at age 43, you can expect there would be *three* DES Daughters of the same age also to experience natural menopause. It holds true in the study that *at all ages*, a greater number of DES Daughters achieved menopause, compared with unexposed women, up through age 54.

The researchers found an increased risk of earlier natural menopause among those who were exposed to the highest cumulative doses of DES in utero. Hatch speculates this might be related to the number of ovarian follicles produced before birth.

She points out that laboratory studies suggest DES-exposed animals start off with a smaller follicle pool, which decreases more rapidly over time than in unexposed animals. Some studies seem to indicate menopause is reached when the number of ovarian follicles falls to 1,100. If a DES Daughter starts out with fewer follicles she'd be expected to reach the set number earlier than a woman with more follicles to begin with, therefore going into menopause sooner.

But Hatch is quick to point out that while this study shows DES Daughters seem to be at risk for earlier menopause, the cause has not been definitely established yet. However, the results do confirm anecdotal evidence collected by DES Action, through the years, from DES Daughters.

This is the first report of prenatal exposure to DES affecting the age of natural menopause, and therefore, suggesting an influence on the reproductive lifespan of DES Daughters.

The researchers found an increased risk of earlier natural menopause among those who were exposed to the highest cumulative doses of DES in utero.

Since more than half of the study participants were still premenopausal when they were questioned in 2001, Hatch recommends the age at natural menopause question be reevaluated when additional information is available. A new questionnaire was mailed to NCI DES Follow-up Study participants earlier this year, so there will be new data to analyze soon. DES VOICE

— See ad on page 7 —

DES VOICE

ASK *the* EXPERT

Our *DES Daughters On Line Support Group* collected questions regarding the new study showing an increased breast cancer risk for DES Daughters over age 40. DES Action member **Jennifer Bailer**, who is an RN working in breast cancer diagnostics, graciously answered our questions. What she had to say was so informative we thought we'd share it with you.

If you are a DES Daughter, and a DES Action member, please consider joining our *On Line Support Group*. See page 2 for easy directions.

Q Given this study indicates we are definitely at increased risk of breast cancer, what preventative measures can we take to lower our risk?

A DES Daughters need to be diligent about keeping up with recommended screenings. The American Cancer Society recommends three things: yearly mammograms, yearly physician exam of breast (clinical exam), and breast self-exams. My musings on these:

1. Keep up with your yearly mammograms, and complete any requested follow-ups in a timely manner. Current recommendations are to get a baseline (first time) mammogram between ages 35-40, then yearly. If you have a mother or sister with breast cancer, talk to your health care provider about what age you should start getting that screening.
2. Get a clinical breast exam by your health care provider every year (along with your 4-quad Pap test, of course).
3. Do your own breast self-exams (BSE) every month. You know your breasts best, so you may detect changes before your health care provider does— but only if you routinely do your BSE. You do not need to know whether a change is good/bad, cancerous/non-cancerous— you just need to notify your provider if there is anything different. There have been some changes made recently to the BSE recommendations. See www.komen.org for a good interactive video on BSE.
4. Other things: Quit smoking, drink only in moderation if at all, maintain an ideal body weight, eat healthy foods, learn about environmental hazards and minimize your exposure to them. Keep in touch with your own doctor and keep your ear to the ground for news about breast cancer and DES.

Q If I have a choice, what should I look for in a mammogram center?

A Because of the MQSA (Mammogram Quality Standards Act), mammogram facilities are required to meet the same government quality standards. There are two things that go above and beyond, however. My personal preference is to go to a facility that utilizes something called an R2 Image Checker machine. This is a computer aided device that flags possible abnormalities on a mammogram and brings them to the radiologist's attention. It doesn't read the mammogram, but does flag certain things that the computer has been programmed to pick up. It has been called a second pair of eyes for the radiologist.

Mammograms are taken in the usual manner then fed through the R2 machine and scanned prior to being read. If your facility uses the R2/ Image Checker it will be noted on your mammogram report. Many facilities use it now. Another option is to seek out digital mammography. *(see next Question).* Resource: www.fda.gov/CDRH/MAMMOGRAPHY/mqsa-rev.html

Q Who should get digital mammograms?

A If you have dense breasts (noted on a mammogram), you might consider getting a digital mammogram. The mammogram is done in the usual way but is not stored on x-ray film. Instead it is digitalized, stored on a computer, and read by a radiologist on a large computer monitor. This allows the radiologist to manipulate the image in certain ways that can aid in reading it more accurately (for example, contrast and brightness can be adjusted, and the image can be magnified). Recent studies have shown that in women under age 50, who have dense breasts, more cancers were detected with digital than traditional mammograms. So far, no benefit has been show for other women, but more research is being done.

DES-exposed women who have not given birth may have dense breasts, making their mammograms especially difficult to read, so digital might be a good option. It may take some digging to find a handy facility that does digital mammograms. Try the larger, university-affiliated hospitals. Make sure you ask for DIGITAL, not to be confused with R2 Image Checker (above). A facility may use both digital and R2, and this is best.

One facility I know of does conventional mammograms, and digital– but you must ask for digital as not everyone gets it automatically.
Resource: www.cancer.gov/newscenter/pressreleases/DMISTQandA

Q What symptoms should we be on the look out for? Are there any potential indicators other than finding a lump? Could breast tenderness, etc., indicate potential breast cancer?

A Look, and feel, for a lump — like a dried pea, a grape, a walnut, or a thickening in an area of the breast. Also, look for changes in the skin - dimpling, puckering, pulling in, a nipple that draws in, a rash that won't go away, a change in contour, such as a flattening on one side, or a sudden change in size of a breast. Pain that comes and goes is usually hormonal.

A systematic approach to breast self-exam is best. Learn and use a good technique, and do it every month. The technique on the Komen web site (www.komen.org) is considered the best one, currently. Women know best about their own bodies, and I never discount a concern a woman has. So if something (pain, or anything else) is worrying you, TELL your health care provider.

Q My breasts are very lumpy so I have a hard time doing breast self-exams. What do you recommend?

A I understand about having "lumpy bumpy breasts." Lumps and bumps that come and go are normal. Don't stop (or fail to start!) your BSE just because you feel lumpy. Do your exams often enough (once a month) so that you get to know how your breasts feel. Then you'll recognize immediately if something changes. Your job is to alert your health care provider if you feel anything different. You don't have to know what it is — let them decide that. Just tell them if you feel a change.

Some women have what we call "pebbly" or "grainy" breasts where it feels like there are lots of pebbles, or grains of sand in the breast. I call this "background noise," and it is normal tissue. However, if something suddenly stands out from the background noise, announces itself, draws your attention to it, or feels different — that would be something to let a health care provider check out. DES VOICE

Some of the questions that came in were scientific in nature, so we asked the study's lead researcher Julie Palmer to answer them. She is at Boston University's Slone Epidemiology Center and has been studying DES issues for many years as a Principal Investigator with the National Cancer Institute DES Follow-up Study.

Q I am a 48-year old DES Daughter. My breast cancer was limited to one breast (which was removed). So, what is the probability of developing cancer in the other breast?

A So far, only one woman in our study has developed two breast cancers. I'm not sure there will ever be enough cases for our study to provide useful information on that, but we will certainly be looking at it. Therefore, we don't know the probability of your developing a second cancer. But given that DES exposure increases the chances of developing a first breast cancer, it may well increase the chance of a second cancer.

Q What does the RR of 1.9 really mean in terms of identifying DES as the causal agent in a particular case?

A The RR of 1.9 indicates that our best estimate is that women exposed to DES in utero have 1.9 times the risk of unexposed women. The confidence interval of 1.09-3.33 tells us that, although the best estimate is 1.9, the true estimate could be as low as 1.1 or as high as 3.3. In our earlier and smaller study, our best estimate was 2.5, but the confidence interval was quite wide. Estimation improves when there are more breast cancer cases in the study. The number of cases almost doubled from earlier analysis to the present one. Therefore, we believe that the strength of the association between DES exposure and breast cancer risk is more likely to be 1.9 than 2.5.

Q What is the impact of hormone use earlier in life (birth control pills, fertility meds, etc.)? Might they be considered a confounding factor?

A We took into account earlier use of birth control pills and found no evidence that use made a difference in the relation of DES exposure to breast cancer risk. For example, the relative risk of breast cancer associated with DES exposure was not stronger among women who had used birth control pills than among those who had not. There were not enough users of fertility medications for a meaningful analysis of whether these medications had an impact. DES VOICE

FDA Warned of Potential New Hormone Tragedy for Pregnant Women and Their Children

by Kari Christianson

DES Action, working with the National Women's Health Network (NWHN), provided written testimony to an advisory committee of the Food and Drug Administration (FDA). The advisory committee was meeting to consider a response to an application for approval of a synthetic progestin drug with the brand name "Gestiva" to prevent pre-term labor. Synthetic progestin has been in widespread use for this purpose without regulatory approval for some time, but the FDA is being asked to give formal approval for Gestiva. In the following letter DES Action expresses opposition to FDA approval of this drug.

On behalf of ten million DES-exposed people in the United States, including over two million women exposed in utero to diethylstilbestrol (DES), we are urging the members of the Advisory Committee for Reproductive Health Drugs to exercise prudence and to deny a recommendation of approval for the synthetic progestin Gestiva for use with pregnant women at risk for pre-term delivery.

The history of reproductive harm caused by in utero exposure to DES gives our population particular personal expertise in addressing the issue of hormones for pregnant women. Because of in utero DES exposure, and quoting from the *2003 Centers for Disease Control and Prevention's DES Update*, "approximately 20% of DES Daughters experience pre-term labor, compared to 8% of unexposed women (Kaufman, 2000)." Additionally, the *Update* states that "any pregnancy of a DES Daughter should be treated as 'high risk' by health care providers."

The National Cancer Institute's research with the DES-exposed population is on-going in the DES Follow-up Study and the list of health consequences for DES Daughters, in addition to pregnancy complications and infertility, includes higher risks for breast cancer, vaginal/cervical adenocarcinoma, cervical neoplasia, uterine fibroids, paraovarian cysts and endometriosis.

This population of DES Daughters, including DES Daughters born in this country as well as throughout the world, would be a target market for Gestiva. However, we can find no indication that trial testing included specific evaluation for safety or efficacy with this population. The structural changes to the reproductive tract of DES Daughters warrant specific study before sending this population down another invalid, ineffective or harmful treatment path.

Of most concern to the members of DES Action is the potential to create yet another pharmaceutical hormone tragedy with pregnant women and the children born to these women. What are the long-term consequences to the females exposed in utero to 17 alpha-hydroxyprogesterone caproate (Gestiva)? We are concerned that previous research on the use of progesterone is being forgotten or ignored. The research studies by Lovell A. Jones and Howard A. Bern about the long-term effects of early exposure to hormones – including progesterone – are particularly worth review and consideration.

Their research, published in 1977 and 1979 in *Cancer Research*, reported neonatal exposure to progesterone treatment alone resulted in vaginal and cervical epithelial lesions in the mouse model similar to that occurring in mice treated neonatally with estrogen, like DES. The neonatal mouse model and the prenatal mouse model have been used successfully to study the effects of DES on humans; these models have replicated and, in some incidences, predicted human health problems. This experience dictates there is every reason to believe that the adverse effects of progesterone in the mouse model are predictive of an adverse outcome to the human reproductive tract, including vaginal and cervical tissue.

We in the DES-exposed community are very concerned that this proposed use of 17 alpha-hydroxyprogesterone caproate (Gestiva) for pregnant women will add yet another chapter to the on-going struggle to understand the human health consequences of in utero hormone exposure. We urge the members of the Advisory Committee to withhold a recommendation of approval for Gestiva.

On a vote of 12 to 9 the advisory committee recommended approval of Gestiva; the FDA has not acted on the recommendation yet. With our partners in consumer health advocacy at the National Women's Health Network and other organizations, we will continue to vociferously remind the FDA not to repeat the hormonal mistakes of the past. But history (fuelled by Pharma greed) seems destined to be repeated. DES VOICE

Generating excitement at DES Action's booth at the annual California Women's Conference. Margo Burton, Maira Phillips, Marilyn Shenker and Patti Negri proudly wore our DES Action T-shirts. The shirts, and smiling faces, drew many of the 14,000 participants to stop by and learn more about DES. To order a T-shirt (available only in black), see ad on page 7.

LETTERS TO THE EDITOR

We very much like hearing from our members and appreciate those of you who take time to get in touch with us. If you have something to say, please don't hesitate to send a letter or email to: 158 S. Stanwood Rd., Columbus, OH 43209 or desaction@columbus.rr.com.

*We reserve the right to edit for space limitations and to select letters of most interest to our members. These letters were received in response to the **Your Voice** column in Voice issue #109.*

Dear DES Action,

I hope you don't mind me commenting on the last *Voice* newsletter — and this is very hard for me. Perhaps it caught me on a bad day but the ***Your Voice*** section was emotionally difficult for me to read.

In my case, and I know of many others where there has been no hope — the results of DES have been devastating. Adoption is almost out of the question here — there are very few babies for adoption. Also many of us are now at an age where we have had to settle with our grief.

I know there are many stories of hope and I am very happy for those people. The diverse impact of DES means we all have very different stories to tell. I hope you don't mind me saying my thoughts about this — I just had to get it off my chest.

Fond wishes,

June (from Australia)

Dear DES Action,

Well, our "family building" efforts are still very much a work in progress.

After one IVF cycle, and a chemical pregnancy, we did another in August. It was negative, which was devastating. So, we are at a crossroads in this journey.

It is harder than I ever imagined to give up on the idea of having a biological child, and of being pregnant and giving birth. This is a desire for my life that I always held dear, and it is painful to think that DES could really and truly rob my husband and me of that chance forever.

When is enough, enough? When do we stop subjecting ourselves to the shots, the long-term risks of the drugs, and the potential disappointment again, just for some more hope...or maybe.…

On the other hand, we are both very open to adoption. We will adopt, I think, but I am struggling with how to feel good about it. I will not do this and think of it as a "consolation" prize, but that is, honestly, where I am right now, and I don't know how I will ever move from point A to point B.

So much of what Elizabeth Kate wrote in the last newsletter spoke to me. Can you ask if she would to talk with me? It's hard being on the young end of this hell because so few DES Daughters are still trying to have kids. Thanks so much for being there. It's good to know you are rooting for us.

Alex (from Vermont)

Editor's note: Elizabeth Kate graciously agreed to talk with Alex about her experiences with adopting one daughter and then giving birth to her second one. DES VOICE

Risks of False Results in Breast Cancer Screening

by Pat Cody

DES-exposed women, both mothers and daughters, have a higher risk for breast cancer than unexposed women. They will have mammograms more often, and need to know about the likelihood of errors in the reading of their x-rays.

"Hormone Replacement Therapy and False Positive Recall in the Million Women Study," E. Banks et al, Breast Cancer Research 2006,8:R8

This study was done in England and covered 87,967 postmenopausal women aged 50-64. Among this group, 3,028 were recalled for a second assessment. A total of 399 were diagnosed with breast cancer, leaving 2,629 with "false positive" recall. The researchers wanted to find out what caused the original erroneous cancer report in this group.

Their survey showed that those who were current and recent users of HRT, whether of estrogen alone or estrogen-progestin combination pills, were at significantly greater risk for receiving this "false positive."

How could HRT play a part in this? The authors found that, "there is evidence to suggest that women who are currently using estrogen-only and estrogen-progestogen HRT have a higher proportion of their mammograms occupied by relatively radiodense tissue, compared to woman who have never used HRT, and this remains a plausible reason for the increase in false positive recall in users."

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"This I Believe" about DES

National media project, This I Believe, collects essays about core values. National Public Radio (NPR) airs selected essays on Monday mornings. DES Action member Caitlin McCarthy contributed one, which is now available in the on line database. Essays are still being collected, so McCarthy suggests anyone with a penchant for writing can submit thoughts about living with DES. http://thisibelieve.org/dsp_ShowEssay.php?lastname=McCarthy&uid=4398&start=0 0

On May 18, 2005, my life changed forever. During a colposcopy — a gynecology follow-up for abnormal Pap smears — I was diagnosed as a DES Daughter. For those who don't know, DES is a toxic, carcinogenic drug that was prescribed to unsuspecting pregnant women in the U.S. from 1938 until 1971. Touted as a wonder drug by some doctors, and bundled in various prenatal vitamins, DES hurt the health — and lives — of millions of people: mothers, daughters, sons, and the third generation of DES-exposed children. Contrary to popular belief, DES is not a dead issue. The tragedy continues to this day.

Up until this year, I had always believed that I'd have children of my own. But now I know that may never come to pass, because the in utero DES exposure caused structural changes in my reproductive organs. In addition to fertility issues, I face a lifelong risk of a rare cancer of the vagina or cervix, known as CCA. And if that's not enough, I could also develop autoimmune diseases such as lupus, rheumatoid arthritis, and Graves' Disease.

After struggling with the shock and sorrow that followed my DES diagnosis, I got off the pity path and started down the war path. I armed myself with knowledge about DES. I joined DES Action USA, an amazing nonprofit group dedicated to helping and advocating for DES-exposed people, as well as educating health care professionals. I also started researching and writing a screenplay about the origins of DES, so I could help alert people to this silent epidemic. Millions of people have no idea that they were exposed to the drug. I didn't know for 34 years. That is unacceptable.

My DES exposure isn't a cross that I bear. I have chosen to view it as a motivator. Sure, there's a chance that I could die from DES-related issues. But I could also get hit by a bus, or die from an aneurysm. Only time will tell.

This I believe: Life cannot be taken for granted. I must make the most out of every day. DES has given me my cause. And I am alive with energy.