DES Action VOICE

Inside

A FOCUS ON DIETHYLSTILBESTROL

WINTER 2007 #111

DES Granddaughters Show Delayed Menstruation Regularity In New Study

Infertility Problems Also Hinted

"Menstrual and reproductive characteristics of women whose mothers were exposed in utero to diethylstilbestrol (DES)," Linda Titus-Ernstoff, et al, *International Journal of Epidemiology*, June 2006.

Reviewed by Fran Howell

DES Granddaughters participating in a recent study reported starting menstruation at about the same age as unexposed women (mean age 12.6-years for both groups), but it took longer for DES Granddaughters to achieve regular menstrual periods (meaning a period is predictable within 5 days).

Health questionnaires for this self-reported study were filled out by 793 individuals, including 463 DES Granddaughters and 330 unexposed females. They are all offspring of women being followed as part of the long-running National Cancer Institute DES Follow-up Study.

Researcher Linda Titus-Ernstoff, Ph.D., found that on average DES Granddaughters attained menstrual regularity at 16.2 years of age, which is slightly later than the unexposed women at 15.8 years.

Titus-Ernstoff is a professor in the Department of Community and Family Medicine and is associate director of the Hood Center for Children and Families at Dartmouth Medical School. She is a Principal Investigator with the NCI DES Follow-up Study and leads the granddaughters study.

According to Titus-Ernstoff, "daughters of the exposed women were more likely to report periods that were usually irregular and at least one episode of amenorrhoea (defined as more than six weeks without a menstrual period during the previous 12 months)."

The study factored in such variables as menstrual and reproductive histories, the number of doctor visits

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Noted Scientist Shares His Thoughts On DES Grandchild Research

"Commentary: Prenatal exposure to diethylstilbestrol (DES): a continuing story," by John A. McLachlan, *International Journal of Epidemiology*, June 2006.

Reviewed by Fran Howell

Researcher John McLachlan, Ph.D., Director of the Center for Bioenvironmental Research, Tulane University, is highly regarded in the DES community.

So his commentary, following Linda Titus-Ernstoff's DES Granddaughter article in the *International Journal of Epidemiology*, is worth noting.

In this article he describes the long scientific search to learn why an estrogen, such as DES, can be given to a mother and then have it cause problems in her offspring. "The DES-exposed population of men and women became the model through which understanding of delayed effects of gestational exposures to hormones or other compounds could be gained," McLachlan says.

After much study he says scientists in laboratories, including his own, have ruled out mutagenicity, or the ability to change the base structure of DNA, as the primary

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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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DES Granddaughters *from page 1*

and hormone use. Not many participants reported using oral contraceptives for other than birth control, but of those who did, DES Granddaughters generally used them longer than the daughters of unexposed women (16.1 months vs. 3.6 months). Stated reasons were for regulation of periods and reduction of menstrual cramps.

Possible Infertility Issues

The study suggests that infertility may be more frequent in DES Granddaughters and DES exposure may exacerbate age-related infertility for them.

Titus-Ernstoff cautions, however, that the study is small and most participants were too young to have attempted starting a family. About 5.4 percent of the DES Granddaughters and 5.2 percent of the unexposed young women in the study reported dealing with infertility, which is defined as difficulty getting pregnant for 12 months or more. After adjustment for age and cohort, the data suggested that DES Granddaughters might be at increased risk for infertility. Interestingly, what the researchers noted is that problems with infertility seemed to increase with age, primarily for DES Granddaughters over age 30. But again, the numbers were very small, and most women hadn't yet tried to start a family.

Among those who had given birth, Titus-Ernstoff says, "daughters of the exposed were slightly less likely to report a live birth, but the relationship was compatible with chance. On average and adjusted for age and cohort, the exposed women had fewer live births than the unexposed." She also found the mean birth weight of babies born to DES Granddaughters was lower than in the unexposed group.

Titus-Ernstoff stresses that this research is preliminary and further follow-up is needed as more DES Granddaughters enter their reproductive years. DES VOICE

Scientist Shares Thoughts *from page 1*

method for DES' effects through generations.

Instead, McLachlan explains that scientists now believe DES causes problems to occur during cell differentiation and formation of organs. He suspects DES changes the normal patterns of gene expression. "In the very simplest terms, skin expresses skin genes, while bones express bone genes; just as importantly, bone-specific genes are turned off in skin and vice versa."

But sometimes something causes the process to go awry, turning off genes that should remain active and turning on others that shouldn't be, all the while leaving the gene code, or DNA, intact. This field of study is called epigenetics. Endocrine disruptors, like DES, have been implicated in improper gene functioning.

McLachlan says work from his laboratory and others, "raises the possibility that early exposure to DES may cause persistent epigenetic changes in some genes and not others such that the fate of tissues or organs is altered." He adds that, "the epigenetic change can actually persist through generations of cells in one organism or, if the change occurs in the germ cell line (egg cells in females and sperm cells in males), could even persist into the next generation of an organism."

The study done by Titus-Ernstoff and her colleagues shows young women, who were not themselves exposed to DES, may have altered reproductive tract function because their mothers are DES Daughters. McLachlan finds it extremely interesting. "This is a remarkable finding, if replicated, since it would mean that in humans, maternal ingestion of DES during pregnancy can not only alter the reproductive capacity of the woman exposed directly while a fetus, but that the alteration may be passed on to another generation (the so-called DES granddaughter effect). The effect described in the current paper, later attainment of menstrual regularization and more irregular periods, is small, but biologically consistent for an oestrogenic effect."

According to McLachlan, this is preliminary evidence that DES can alter the way genes work in certain cells so that the changes, not to DNA but to the way genes function by turning on and off, can extend into future generations. "More than half a century of DES experience has shown us that numerous defects can be encoded in the genome of the exposed fetus to be expressed later in life. This paper (by Titus-Ernstoff) and the supporting animal research data suggest that these encoded or imprinted defects may, in some cases, persist into the next generation. This is a small study with many questions, but the questions are profound enough that they merit an enhanced and continued follow-up of DES-exposed offspring and their offspring."

This is preliminary evidence that DES can alter the way genes work in certain cells so that the changes, not to DNA but to the way genes function by turning on and off, can extend into future generations.

Finally, McLachlan gives a nod to Arthur Herbst, M.D., who first alerted us to the fact that DES given to pregnant women could cause cancer in their daughters. "It is notable," says McLachlan, that 35 years later, Herbst may be "illuminating the first example of transgenerational effects of DES in humans as one of the authors of the current Titus-Ernstoff paper." DES VOICE

ASK *the* EXPERT

A new child and adolescent vaccination schedule has been issued by the Centers for Disease Control and Prevention following last year's FDA approval of the HPV vaccine, Gardasil. It was developed by the drug maker Merck to protect against cervical cancer, precancerous genital lesions, and genital warts due to HPV types 6, 11, 16 and 18.

The new vaccination schedule calls for the cervical cancer vaccine to be given to girls aged 11 to 12, in three doses. After the first one, the second should follow in two months and the third dose should come at least four months after that. But if circumstances warrant, the CDC says the vaccinations can begin as early as age nine. Catch-up vaccination is suggested for girls between the ages of 13 and 18 if not previously vaccinated. Most doctors tend to follow vaccination guidelines set forth by the CDC.

Participants in the ***DES Daughters On Line Support Group*** had lots of questions about this new cervical cancer vaccine. So we collected them and asked the chairman of the University of Chicago Department of Obstetrics and Gynecology, **Arthur Haney, M.D.**, to help sort out fact from fiction for us. Dr. Haney has been involved with scientific research into DES for many years and is considered a leading expert on infertility issues.

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 When the vaccine was studied before approval, was DES exposure considered at all?

A In a word, "no," there was apparently no consideration given to DES exposure in the trials done by Merck. I have seen nothing indicating that DES was segregated out. In fact, it was tested in women up to 26-years old and so they were too young to have been exposed to DES in utero. While I understand concerns in the DES community about any new medication, I want to allay anxiety in this case. I firmly believe this vaccine is safe for exposed and unexposed individuals when administered by a health care provider.

Q Can you tell us how the new cervical cancer vaccine works?

A This vaccine is not a toxic agent. It is designed to awaken a person's immune system to respond to, and attack, the human papilloma virus (HPV), which is the primary cause of cervical cancer. The vaccine is not made from an active virus, but rather it was developed from the outer membrane or coating surrounding the DNA of the HPV virus. By taking the vaccine, a person should presumably develop antibodies against the outer shell of the sexually transmitted virus, not the virus itself. That seems to be protection enough against HPV-caused cervical cancer and genital warts.

BUT — this is important for DES Daughters to understand — the vaccine works against cervical cancer caused by HPV, and has no effect what so ever against Clear Cell Adenocarcinoma of the cervix and vagina, which is the cancer linked to DES exposure.

Q I'd like to know the recommendations for teenagers. With a 15½ year old, I am definitely planning on getting it for her. I'm assuming it should be given ASAP, but up until what age?

A The optimal use of the vaccine is for pre-sexually active women, which is why it is now recommended for individuals between the ages of 9-26 years old. With no exposure to sexually transmitted viruses the vaccine gives them protection against the four main subtypes of HPV viruses affecting American women. (There are different ones in other parts of the world). That said, I'm sure the upper age limit recommendation won't hold up over time, and here is why. The vaccine provides protection against four HPV strains, subtypes 16 & 18 which are related to cervical cancer, and subtypes 6 & 11 which generate genital warts. If a more mature woman comes in with HPV caused dysplasia (abnormal cells on the cervix that can progress into cancer), it means she has definitely come into contact with at least one HPV subtype. But she might still want the vaccine to protect against the other main cancer-producing strain - presuming she has not yet been exposed to it — and, admittedly, that is difficult to know. Also, she may want to protect against genital warts by taking the vaccine. The more sexual partners a woman has had, the more likely it is that she has already been exposed to the HPV virus strains in the vaccine, so it wouldn't do any good. That is why younger, and presumably less sexually active, is the best bet for vaccination protection.

Q Can the vaccine be given to a young woman who is already sexually active? Is it still advisable to do so?

A If her sexual history is fairly limited, it might make sense to seriously consider the vaccine to protect against the various strains of HPV in the vaccine. If she has already come into contact with HPV subtype 6, then she will have no protection against that strain of genital warts. But the vaccine will protect her against the other type common in America, HPV 11, if she has not yet been exposed to

it. Also, she might not yet have encountered HPV subtypes 16 and 18, which means vaccination will protect her against dysplasia and possible cervical cancer. I know you are going to ask if there is any way to tell whether exposure has occurred to different strains — and the answer is no, there is no good way to do so at the moment. That's why the vaccine is recommended for young, pre-sexually active women.

Q Should I, as a 41-year old woman, get the vaccine? Is it helpful to us at such a late age?

A Possibly. Lifestyle is an important variable. If a woman has been monogamous for 20 years and her husband has just died, she might want to consider the vaccine before starting to date again. There is a good chance she has not been exposed to at least some of the HPV strains the vaccine protects against. Otherwise, a 41-year old married woman who is not meeting new sexual partners probably would not benefit from vaccination because she is not being exposed to the sexually transmitted HPV viruses that cause a majority of cervical cancers.

Q As a DES Daughter, I'm concerned about this new vaccine. Am I right to be?

A I do not believe that DES Daughters will respond any differently to this vaccine than unexposed women. The vaccine is designed to stimulate a woman's immune system. Even though early DES research indicated the possibility of a different immune response, there is no evidence in human studies, so far, that shows a significant difference in immune system functioning between exposed and unexposed women, especially when it comes to vaccines. DES Daughters successfully take all sorts of vaccinations, from rubella to pertussis to the flu vaccine. This one should be no different. Unlike, for example, the polio vaccine, which is a weakened infectious agent that could possibly spread the virus to an immuno-compromised individual, the cervical cancer vaccine we are discussing here is not an active virus at all.

Q Will this vaccine protect against the cervical cancer that DES Daughters are at higher risk for getting?

A No, absolutely not. Clear cell adenocarcinoma (CCA) of the cervix and vagina is a completely different type of cancer than the one this vaccination is designed to protect against. As a result, all DES Daughters should continue having annual Pap/pelvic exams to check for the DES-linked cancer. Don't forget, even if a DES Daughter has a hysterectomy, she should still have her annual exams. While her cervix was removed in the surgery, her vagina is still vulnerable to clear cell adenocarcinoma.

Q I've heard that DES Daughters are at higher risk for getting HPV than other women. Does that mean we are good candidates for the vaccine?

A Many DES Daughters have a larger cervical transformation zone than unexposed women, and that's where the HPV virus invades cells. With a bigger area, clearly DES Daughters may run an increased risk for HPV infection. But we are seeing that as DES Daughters age, their cervical transformation zones often shrink back to normal size. Then, we must remember that most DES Daughters are not teenagers anymore. They have probably been sexually active through the years and may have been exposed to some of the main strains of HPV. As a result, I don't think a majority of DES Daughters will actually be good candidates for this vaccine.

Q What about my teenage daughter, who is a DES Granddaughter. Is it safe to give her the vaccine?

A This is a decision you'll want to make in consultation with your daughter's doctor. I understand your concerns because we know so little about how DES might have affected this group of young women. It is a case where you must balance the risks versus the benefits of the vaccine. At this point, though, I don't see any major warning signs against giving the vaccine to DES Granddaughters.

Q My daughter is currently on the waiting list at her doctor's office. They have not yet gotten the vaccine. Is there a shortage?

A I have not heard of any distribution problems with the vaccine, but of course there could be sporadic and regional ones. At this point, though, nothing of a national scale problem has come to my attention. The doctors likely to be giving the most vaccinations are pediatricians because of the currently stated age recommendations. I suspect that eventually cervical cancer vaccinations will fall into sequence right along with other childhood vaccinations, and will become fairly routine.

Q Are there any high-risk groups which should be given/ should not be given the vaccine?

A Other than the above mentioned caveats regarding timing for optimal use, no. It is not recommended for pregnant women but that is not based on a demonstrated risk, simply the usual caution regarding any preventative medication during pregnancy that is not treating an active problem.

Q I have read that the actual numbers of women with cervical cancer is fairly low, and that drug companies stand to make huge, huge profits by recommending all women get vaccinated. Isn't a regular Pap smear good enough?

A The risk of actual invasive cervical cancer is lowered by the use of both screening Pap smears and treatment of pre-invasive cervical dysplasia.

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HRT and Breast Cancer: Two New Reports

By Pat Cody

"Recent Declines in Hormone Therapy Utilization and Breast Cancer Incidence: Clinical and Population-Based Evidence," Christina A. Clarke, et al, *Journal of Clinical Oncology,* 20 Nov. 2006.

The authors begin this report by reminding readers that "long term use of estrogen- or progestin- containing hormone therapies (HT) is well recognized to be associated with increased risk of breast cancer…."

The other side of such findings, as it were, is this new study that shows a direct connection between a drop in HT use and a drop in breast cancer cases for women ages 50-74. Study subjects in the Kaiser HMO for northern California showed a 68% decline in HT prescriptions between 2001 and 2003, and a 10% decline in breast cancer incidence for women in that group. The researchers add that for 2004, breast cancer incidence in this group and in the state were still lower than the rate for 2003.

"Breast Cancer Incidence Falls Along with Hormone Replacement Decline," Peter M. Ravdin, et al, San Antonio Breast Cancer Symposium, 15 Dec. 2006.

Dr. Ravdin's group looked at studies from the National Cancer Institute's epidemiology data and found that between 2003 and 2004 there was a drop nation-wide of 7% in breast cancer incidence. This means a decline of about 14,000 cases a year, which is significant since breast cancer is the second leading cause of death among women. Looking only at women ages 50-69, the decline was 12%. Dr. Ravdin said that, "what we think is going on is that about half of the cancers that were just below the detection range in 2002 in women who were taking hormone replacement therapy actually stopped growing or regressed when they stopped (HRT)."

The Clarke study covered only women in northern California while the Ravdin report was for the entire United States. Accordingly, we cannot add the 11% drop from 2001-2003 in Northern California and the 12% drop from 2003-2004 for the entire United States, and say we see a 23% drop from 2001-2004. But we can surmise that the decline would be substantial. DES VOICE

An Editorial Comment from Pat Cody

Since the first year of the *VOICE*, in 1979, we have urged caution about the use of hormone pills by DES-exposed women. By now, we have had around 30 articles on this topic, all of them based on research reports by well-accredited sources.

So we find it dismaying that Dr. V. Craig Jordan, science director of the Fox Chase Cancer Center in Philadelphia, told *N.Y. Times* writer Gina Kolata (26 Dec. 2006) that, "We've known there is a cause and effect with hormones and breast cancer since 1986…." But later he says that, "Throughout the 1990's physicians were recommending that menopausal women take hormone replacement therapy. What happens is that you increased the rate of breast cancer in the whole country…."

And yet Donald Berry, a senior researcher at the M.D. Anderson Cancer Center in Houston, told Ms. Kolata (*N.Y. Times* 15 Dec 2006) that the connection between the drop in rates and hormone use is "astounding."

Where have you been, Dr. Berry, Dr. Jordan, and all the physicians who have access to the same reports that we do? And who either prescribed or stood silent as study after study showed the harmful effects of hormone drugs? Those of us at DES Action have known this story for 36 years. It is we who are surprised that after all these years you find this information surprising, given that we have known since 1971 about the connection between hormones and cancer. DES VOICE

Ask the Expert *from page 5*

As a result, the incidence of cervical cancer is lower in this country than in other parts of the world because women are routinely screened. Unfortunately, HPV-related cervical dysplasia is very common and detected often, so the goal of this vaccine is to reduce the likelihood of developing cervical dysplasia and also genital warts. The intent, really, is to avoid the need for treatment of dysplasia, genital warts and ultimately cervical cancer.

Q I hear there is a second vaccine for HPV coming out. Should women wait for the next one to see which is best?

A That is an unanswerable question at present without a head to head comparison of the effectiveness of the vaccines. However, the currently available vaccine has been shown to be very effective against the two most common HPV subtypes associated with cervical cancer (16 & 18), as well as the two HPV subtypes associated with genital warts (6 & 11). For women who are not planning to begin sexual activity for over a year, waiting may be a rational choice, but given the effectiveness of the current vaccine, it is hard to imagine how waiting will be helpful. Remember, it takes three doses of the vaccine over six months to become maximally effective, so this should be a proactive decision well in advance of the initiation of sexual activity. DES VOICE

A New Way To Teach Doctors About Drugs

DES Action member participates in exciting project

When DES Action Executive Director Fran Howell goes to the doctor, she proudly wears her DES Action *Bad Karma for Big Pharma* T-shirt because it is almost guaranteed that a drug company representative will be there, too. While she gets lots of curious stares, so far not a single drug rep has dared inquire about the slogan. That's not surprising as they are busy planning how to convince her doctor to prescribe the high-priced name brand drugs their companies are promoting.

DES earned big profits for drug makers, who heavily promoted the synthetic estrogen so doctors would prescribe it often. But research published in the *Journal of the American Medical Association* back in 1953 showed DES failed to prevent miscarriage. So drug companies, like Eli Lilly, worked that much harder to overcome this fact.

They went into overdrive with advertising and promotions to help doctors forget what the published study had shown. It worked, because an estimated four million DES prescriptions were written, most after 1953. Drug reps, often called drug detailers, are good at what they do in helping shape the prescribing decisions made by doctors.

But what if physicians could learn about drugs in a different way? Harvard Medical School Professor Jerome Avorn has set up a team of so-called "unsales representatives" who, like drug reps, visit doctors. Instead of promoting a particular drug, they share unbiased information and research about the safety and effectiveness of various drugs. These academic detailers aren't selling anything. Instead, they provide doctors with valid research, which in turn, it is hoped, will result in them prescribing the most effective treatments for their patients (www.rxfacts.org).

The state of Pennsylvania has contracted with Avorn and is funding an unsales team to work there. DES Action Member Jean Golomb, who also served as a member of the DES Action Board of Directors, is on that team.

> "While drug reps bring handfuls of office supplies emblazoned with drug logos, the academic detailers offer knowledge."

"Doctors are busy, so it isn't easy getting even a few minutes with them. But I stop by and use the same tried and true techniques as drug reps, such as handing out visually appealing educational materials, brochures and learning tools for patients. Once I get a foot in the door and they understand I'm there to offer valid scientific data, they are happy to see me when I come back," Golomb says.

"I provide doctors with the latest research in an easy to understand format. I don't take up a lot of time, sometimes as little as 10 minutes. And the fact the content is developed by Harvard faculty is a huge help," says Golomb.

For example, during visits academic detailers might remind doctors that the highly advertised anti-inflammatory arthritis drug Celebrex costs about $80 a month, while over-the-counter alternatives like naproxen or acetaminophen (Tylenol) cost around $9 for a month's supply. Both have been shown to work effectively, and if not strong enough then doctors are urged to consider different prescription generics along with other options for handling serious pain.

While drug reps bring handfuls of office supplies emblazoned with drug logos, the academic detailers offer knowledge. Doctors have their choice of one of several medically-related books including Avorn's, *Powerful Medicines: The Benefits, Risks and Costs of Prescription Drugs*. After meeting with an academic detailer, a physician can take a short test to receive continuing medical education credit from Harvard Medical School.

In a New York Times Op-ed piece published on 9/16/2006, Avorn writes, "much of my work is about defining which medications work best for which conditions, and how to close the gap between that knowledge and the care patients typically receive. My research group constantly comes across effective treatments that are underused, and poor-choice drugs that are widely prescribed. Even when good clinical trial data on a regimen or medicine exist, no coherent system ensures that the message gets out to doctors and patients. As a result, many treatment choices are driven by habit, old information or glitzy promotional campaigns."

As a DES Daughter, Golomb wonders whether years ago a program like this could possibly have limited the scope of the DES tragedy. "Doctors who were bombarded with fancy advertising about DES back then might have been grounded by an academic detailing force carrying the 1953 study showing DES didn't work. Doctors could have been reminded that miscarriages are a natural part of nature, meaning drug intervention isn't necessarily needed in subsequent pregnancies. And finally, if academic detailers had been around then, other anti-miscarriage options could have been suggested, perhaps bed-rest," she says.

"Think of all the suffering that could have been prevented. We are seeing that doctors like getting pharmaceutical information that doesn't come from someone working on behalf of a drug company. I hope this experiment is successful in Pennsylvania and then spreads throughout the country," says Golomb. DES VOICE

DES Action VOICE

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