DES Action VOICE

A Focus On Diethylstilbestrol

SPRING 2010 #124

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DES May Increase the Risk for Depression in Those Exposed Before Birth

"Diethylstilbestrol Exposure in Utero and Depression in Women," O'Reilly EJ, et al, *American Journal of Epidemiology*, Vol. 171, No. 8, March 2010.

Reviewed by Fran Howell

One of the questions most frequently asked of DES Action USA is whether DES exposure increases the risk for depression and anxiety in DES Daughters and Sons. We now have results from a large study (76,240 individuals) that finds it very well may.

Using information gathered from participants in the Nurses' Health Study II, Harvard School of Public Health researcher Eilis O'Reilly, Sc.D., and the research team compared responses from those who indicated they were DES-exposed and those who said they were not. The conclusion is that "neurophysiologic effects of in utero exposure to DES could lead to an increased risk of depression in adult life." However, it is also possible that knowledge of DES exposure could be responsible for the higher rates of depression.

The Nurses' Health Study II has sent health questionnaires to participants every two years since 1989. Starting in 1993, the survey included questions about DES exposure and the use of antidepressant drugs. Participants were asked if they had used such drugs at any point in their lives and if they "ever had two weeks or longer when nearly every day they felt sad, blue or depressed for most of the day."

According to O'Reilly, from the 1993 questionnaire "a past history of depression was reported by 13.8% of the women exposed to DES in utero and by 10.8% of those not exposed." The 2001 results show similar numbers, with depression reported by 19.7% of DES Daughters compared with 15.9% of those not exposed. Adjustments in the calculations were made for depression risk factors such as smoking, alcohol use, income, physical activity and infertility — which were reported at a higher rate by DES Daughters.

O'Reilly acknowledged that the study depends on self-reported use of antidepressants and depression symptoms rather than a physician's diagnosis. Also, DES exposure was self-reported without confirmed medical records. But a subset of participant's mothers was sent a separate survey. Their responses associated closely with their daughters, and therefore added confirmation to the self-reported DES exposure. O'Reilly says strengths of the study are that it is both large and has accumulated information over many years. DES VOICE

DES Link To Early Onset Of Uterine Fibroids Is Unclear In New Study

"Association of Intrauterine and Early-Life Exposures with Diagnosis of Uterine Leiomyomata by 35 Years of Age in the Sister Study," Amiee A. D'Aloisio, et al, *Environmental Health Perspectives*, Vol. 118, No. 3, March 2010.

Reviewed by Kari Christianson

The Sister Study is a new ten-year research project, following 50,000 sisters of women who have developed breast cancer, conducted by the National Institutes of Environmental Health Sciences (NIEHS). This study includes a complete history of all previous exposures and the current health of the women. In addition to seeking clues about environmental exposures that may result in breast cancer, other health outcomes may be found by the researchers as they analyze the health histories.

The first published research of the Sister Study focuses on uterine leiomyomata (fibroids). The researchers report a greater risk of early diagnosis for uterine leiomyomata (fibroids) in women exposed to soy formula during infancy, maternal diabetes and

continued on page 3

DES Action

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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.

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MISSION STATEMENT

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Uterine Fibroids *from page 1*

premature birth. Prenatal DES exposure also was linked to a diagnosis of uterine fibroids before the age of 35.

Interestingly, women in this study with "definite" prenatal DES exposure did not have the same increased risk of an early uterine fibroid diagnosis as women who listed "probable" DES exposure.

As the researchers report, "Given our inconsistent associations for women who report definite versus probable in utero DES exposure, conclusions from our study are unclear."

This lack of clarity about a link between prenatal DES exposure and an early diagnosis of uterine fibroids is not new in the research community. The 2005 NIEHS Uterine Fibroid Study linked prenatal DES exposure and uterine fibroids. And earlier studies with the animal model also found DES exposure linked to later development of uterine fibroids. However, another 2005 study, this time by the National Cancer Institute's DES Follow-up Study, did not find these results among their participants with definite prenatal DES exposure.

The association seen in this study between maternal diabetes and uterine fibroids is of interest to the DES community, as well. Pre-pregnancy diabetes was one of the surest ways for a woman to be prescribed DES during her pregnancy.

While this report may not offer clarity on the link between DES exposure and uterine fibroids, the question itself continues to defy complete understanding. It once again proves that the complexity and timing of prenatal DES exposure — and exposure to all hormonally active substances — warrants additional study. DES VOICE

The Sunshine Act Is Now Law

By Kari Christianson

The DES-exposed community knows firsthand that drug companies don't always tell the whole story. New federal legislation calls for creation of a public website where we can check how much financial influence a drug company is seeking to have on our doctors.

Health care reform legislation recently passed by Congress and signed into law by the President includes the Physicians Payment Sunshine provisions. DES Action USA has been part of a group of consumer organizations, the National Coalition for Appropriate Prescribing, which advocated for this legislation. Consumers want and need transparency about drug company influence on physicians.

The new law requires drug and medical device manufacturers to publicly report gifts and payments to physicians and teaching hospitals. All financial payments or in-kind gifts, such as food or conference funding, must be disclosed. The law exempts reporting of gifts less than $10; however, if the total of gifts by one company reaches $100 for a physician, the company must retroactively report those gifts.

Reporting begins on January 1, 2012. The Health and Human Services Department (HHS) will post all information by March 31, 2013, on a public website. This site will be updated annually. Several drug and medical device companies are already disclosing these types of gifts on their own websites, but the HHS site will be user friendly for all consumers.

DES Action and our partners in the National Coalition for Appropriate Prescribing, along with many other partners and members of Congress, are proud of this successful outcome for consumers. DES VOICE

"Author-Meets-Critics" Panel Discusses DES Book

DES Action USA member Susan Bell, author of *DES Daughters: Embodied Knowledge and the Transformation of Women's Health Politics*, says she was thrilled by the honor given to her by Eastern Sociological Society President Rosanna Hertz, who set up an "Author-Meets-Critics" panel. The expert critics gave careful attention to Bell's book and situated it in the fields of sociology and women's health. They described its contribution to scholarship and the many paths it opens for discussion. Bell was asked to expand upon parts of her book that the critics wished she had included in more depth or handled a bit differently. Bell was particularly moved by the audience response, which included many of her former students from Bowdoin College, DES Daughter Caitlin McCarthy, and McCarthy's father, who was given the last word. His comments were candid, eloquent and emotional in describing the legacy of DES exposure. It was a fitting ending to a lively event, consistent with the spirit and argument of the book.

Photo provided by Caitlin McCarthy

Breast Cancer "Prevention" Drugs Pose Questions

DES Daughters Wrestle With Decision To Use Them

By Fran Howell

Tamoxifen has been found to lower the risk for breast cancer by interfering with estrogen activity in the body. But it has side effects and many women at heightened risk for the disease are shying away from using it. A recent University of Michigan study published in *Breast Cancer Research and Treatment* found that women are reluctant to take tamoxifen, especially after learning of its side effects. They include uterine cancer, blood clots, cataracts and hot flashes.

This study did not specifically look at how DES Daughters feel about tamoxifen, so we posed the question to our members who participate in the **DES Action DES Daughter On Line Support Group** listserv. (See page 2 to join). We asked what they decided when a doctor recommended tamoxifen.

I decided that they don't know enough of what they're doing with tamoxifen. To me it's another DES. Having already been through both breast and uterine cancer, I wouldn't dream of taking tamoxifen after my experiences with DES. I am going 100% holistic. Just my nickel. Your mileage may vary. Health to all of us!

— Mary-Ellen

Just before my 39th birthday, I went in for my second mammogram. I was asked to come back because they "saw something" which might be DCIS (ductal carcinoma in situ – cancer that has not invaded nearby tissue). A biopsy confirmed DCIS, but lumpectomy also showed a small amount of invasion. I was a new mother, and absolutely terrified. I went from praying for it not to be cancer, to praying for it "just" to be DCIS, to pleading that I would not need chemo. Thankfully, there was no lymph node involvement, so the tumor had not spread. I would probably not have taken tamoxifen, given my DES exposure, had it been only DCIS, but once the possibility of a more dangerous kind of cancer became real for me, I decided I wanted to do everything in my power to prevent a recurrence. (My mother had breast cancer at 49, but she is in remission and doing fine at 70). I want to be alive to see my son grow up. I have so much to live for, and see clearly that nothing in life is guaranteed. So, I take my tamoxifen every day. It's been four months, and so far, the side effects are not bad. For my peace of mind, I decided I must do everything the convergence of scientific opinion tells me to do to bring down my chances of recurrence, given my age, even if I am conflicted about it.

— Alex

I have been fighting with myself on this issue for six months. In September it was recommended that I take "chemoprevention" to decrease my estrogen. Due to a blood clot years ago I can't take tamoxifen so I was given another "anti-estrogen." Side effects on this one are hot flashes, osteoporosis and joint pain and a few other goodies. First I went to an oncology dietician and started an "anti-estrogen" diet. That has been great and I lost 14 pounds but not enough. So due to changes in my mammograms last week, I decided to start the tablets. Well I took just one pill and woke up soaked from the sweats. The next day I thought I would pass out from a hot flash. This morning I woke up with stiff fingers. All the time I am saying "this can't happen so fast." Only three days! So I halved the dose. Now I am torn between whether this is the 'antidote' for my DES exposure or another poison to kill me off later. For now I will take half the dose and see. I decided if I gain weight or get carpal tunnel again the tamoxifen is going down the toilet and I will take my chances. Not scientific or rational but that is where I am!

— Carol

Editor's Note: It is best to confer with your doctor before adjusting or stopping medication doses.

DES VOICE

Fool Me Once… The Dilemma of a DES Daughter

By Joyce Bichler
Deputy Director, Breast Cancer Action and author *DES Daughter: The Joyce Bichler Story*

It's been strange lately. It seems the older I get, nearly every medical professional I see is trying to push drugs on me. What I'm hearing puts a chill up my spine. It usually starts like this… Doctor says, "You're at higher risk for breast cancer because of your DES exposure. Eli Lilly makes a drug, Evista, that prevents breast cancer. This drug might be worth trying." I find these conversations more than a little disturbing.

I'm a DES Daughter who had clear cell adenocarcinoma of the cervix and vagina at the age of 18. Don't my doctors know this was because of a drug given to my mother to 'prevent' miscarriage? The frightening thing is YES they know and yet they still make these recommendations! Ironically, because my DES exposure has put me at a higher risk of breast cancer they feel justified in suggesting these medications to me.

My answer to my doctor is al-

ways the same. It's a version of "No thanks. Fool me once shame on you, fool me twice shame on me." But then I wonder, have I done the right thing? I don't want to get breast cancer. Is there any evidence to support taking these hormonal treatments even without having any history of breast cancer?

So let's talk about the evidence and what we really know (and don't know) about two breast cancer 'prevention' drugs — tamoxifen (trade name Nolvadex), and raloxifene (trade name Evista).

First of all, do these drugs actually prevent cancer? Because a portion of those taking tamoxifen or raloxifene will develop breast cancer (even if at lower rates), women's health advocates argued successfully to the FDA that these drugs could not be labeled as preventing breast cancer, but only as lowering risk. Therefore, health professionals should not be using the word *prevention* when talking to patients about these medications. Moreover, these medications have been problematic in at least three major areas: 1) lack of long-term follow-up; 2) producing significant side effects in healthy women; and, 3) misleading reports of findings.

No Long Term Follow-up

In the rush to bring drugs to market, ending clinical trials early is becoming increasingly common and controversial, as a 2005 article in the *Journal of the American Medical Association* (JAMA) stated. Breast cancer often develops over a period of a decade or longer. When a trial is stopped after several years, we cannot derive information about the persistence of the protective benefit. Does the medication actually prevent cancer, or just delay its development? For the drugs in question the follow-up time is too short.

Side Effects

We know tamoxifen has significant side effects. Milder effects include hot flashes and vaginal dryness. The more severe risks include endometrial cancer, pulmonary emboli (blood clots in the lung), stroke, deep vein thrombosis, and cataracts. After many years of study, the drug was found to significantly increase the risk of uterine sarcoma, an uncommon and dangerous form of cancer of the uterus. (Tamoxifen is officially listed as a cancer-causing agent on the list of carcinogens reported by the US Department of Health and Human Services.) Raloxifene is portrayed by the NCI as being safer than tamoxifen, but the published results show that the differences between most of their side effects are not statistically significant (*JAMA*, published online June 5. 2006). The exceptions were that raloxifene users had fewer deep-vein blood clots and cataracts than tamoxifen users.

In preventive medicine, only very minimal risks are considered acceptable—such as those from vaccination or vitamins. The prevalence and severity of the side effects of tamoxifen and raloxifene have led to the coining of a new term in a 1992 Lancet article, "disease substitution."

Misleading Reporting of Findings

A third major problem with the 'prevention' medication studies has been misleading reporting of results. It has become common practice to make public announcements of results prior to peer-reviewed publication. Such announcements often present findings in the most positive manner, and create a media outpouring that is often positively skewed, exaggerated, and misleading.

An example of statistical manipulation comes from the preliminary findings of the STAR trial, which found both raloxifene and tamoxifen reduced breast cancer incidence by 50%. This sounds like a huge difference. But when one looks at the absolute versus the relative risk a different picture emerges. *(Relative risk is the probability of developing a given effect if a drug is used, divided by the probability of developing that effect if the drug is not used. Absolute risk measures the number of people who experienced a particular effect of a drug in relation to the total number of people who were treated.)* Of the 9,700-plus women in each drug group, about 167 got breast cancer. This translates to 1.7%; whereas, 3.4% of them would have been expected to develop breast cancer had they not taken a drug. This is a relative risk reduction of 50%. But another way of saying the same thing is that 96.6% of these women would not have gotten breast cancer whether or not they took raloxifene or tamoxifen. With taking the drug 98.3% were found to not get cancer. This resulted in an absolute difference of 1.7%. Both numbers are true, but without the full picture the impression is quite different.

The approach to so-called breast cancer prevention pills usually works like this: they are prescribed as treatments for advanced breast cancer, then expanded to treat women with early breast cancer, and finally promoted to lower risk in women without any symptoms. This phenomenon has been referred to, in the 2003 *New York Times* article, as "prevention creep." A disturbing consequence of this is a push in the medical community to boost the number of people taking drugs to lower their risk for cancer. The American Association for Cancer Research (AACR), funded in large part with drug company money, has a Chemoprevention Working Group that advocates "widespread implementation of chemoprevention of cancer." They propose broad education directed at physicians and "society as a whole" to accomplish their objectives. The centerpiece of this educational campaign is to "correct" the "misperception" that healthy people should not be treated with possibly harmful drugs!

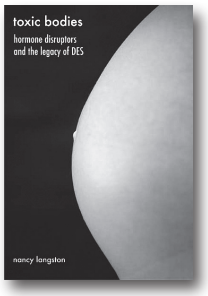
In summary, this is a cautionary tale of yet another Pharma effort designed to promote sales of products with questionable results and without clear evidence of safety to large populations of women. Women deserve to be fully informed about the benefits and risks of breast cancer risk-lowering drugs before making a personal decision about whether to take them. Before I agree to take a drug for a condition I don't currently have, I will need considerably more evidence demonstrating benefits over risks. For now, I'll take a pass on Evista. I do believe my dear mom would be glad to know we won't be fooled again. DES VOICE

BOOK REVIEW

A Fascinating and Disturbing Story of DES and Failed Government Regulation

Reviewed by Pat Cody

Toxic Bodies: Hormone Disruptors and the Legacy of DES, by Nancy Langston, Yale University Press, 2010, $30.00.



When we found out about DES, one of our first questions was "How did this happen? Where was the FDA?" Here is the answer in a well-written account by Nancy Langston, Professor of Forest and Wildlife Ecology at the University of Wisconsin in Madison. Her concern about the changes she sees in the wild life she studies led her to investigate why we were not protected. She discovered that DES was the first test case of the responsibility of government to safeguard public health — and what an uphill struggle it has been. She tells us how the FDA departed from its original commitment to the "precautionary principle" when in 1947 "the agency was telling critics of DES that it was up to them to prove that DES had caused harm, rather than up to the drug companies to show that it was safe."

Further, she writes, "Cultural assumptions about women affected the development, approval, and marketing of DES. The urge to control the disorderly nature of the hormonal female body was closely linked to a sense that women were flawed by nature, unable to make rational decisions without the careful guidance of the experts. Because the FDA did not trust female patients to evaluate medical information, regulators insisted that the warnings be made available on a separate circular that patients would not see. Doctors could get this warning circular only by writing to the drug companies and requesting it."

Once this market was safe, drug companies turned their attention to approval of DES in livestock feed. This was started in 1954 with Eli Lilly's marketing of Stilbosol. Langston reports that by late 1955 "fully half the cattle in America were receiving DES. Soon 80 to 95 per cent of cattle received DES." (As we recall, this use did not end until 1980. But Lilly went on producing DES, marketing it as a treatment for prostate cancer, until 1997. It is still available from Lilly's subsidiary Elanco to treat incontinence in dogs and cats.)

Thus, everyone in the U.S. who was not a vegetarian was exposed to DES for 26 years. Could this have something to do with the decline in male fertility over the past decades? And is this decline also related to the other toxics with estrogenic properties, such as pesticides? Langston has provided a service with her detailed study on how our man-made environment is affecting all the ways we live. The more we learn, the more wisdom there is in having your own garden — or buying organic wherever possible. And the more important the precautionary principle. DES VOICE

Remembering Cynthia Laitman

By Michael Freilick and Kari Christianson

The DES community lost one of our champions and best friends in February, when Cynthia Laitman died. In 1981 she wrote the landmark book, *DES: The Complete Story* (under the name Cynthia Laitman Orenberg), in which she explained how DES exposure had harmed our health and fertility.

As a DES Mother, medical writer and true activist, Cynthia knew what information we wanted and needed. Her book covered every aspect of DES and everyone who was affected by it. Even today, though no longer in print, it remains a definitive work on DES exposure.

Cynthia went on to build a long and productive career as a medical writer, working for the University of Wisconsin Department of Surgery, the National Wildlife Health Center, the World Health Organization, and as the managing editor of the *Annals of Surgery*. She also worked on a National Cancer Institute pilot DES education program and the CDC's DES Update. For Michael especially, it was personally meaningful to work on these campaigns with Cynthia. Her devotion to the health issues of DES Sons was tireless.

These opportunities for us to work with Cynthia grew into enduring friendships. She was always there for us when new health questions arose or to share news about our families. She was one of the most caring people we have ever known.

One additional note about Cynthia — she was fun! No one worked or lived with more passion and joy than Cynthia. Whether presenting DES information to health care providers, putting the final "perfect" edits on an article, or dancing in the aisle at a Tinto Puente concert, she was fully engaged. She was that rare combination of accessible, knowledgeable and joyful.

Cynthia often inscribed her book with these words; we now dedicate them to her: To Cynthia, DES Activist and dear friend! DES VOICE

LETTERS TO THE EDITOR

We are pleased to know that many of you found our article about mammography guidelines published in the last VOICE newsletter (issue 123) was helpful. Several letters have come in recently which are of interest, including the first one here, from a Canadian member who successfully advocated for the screenings she needs by using the information we provided.

—The Editor

To the Editor:

Thank you so much for including the article on updated guidelines for yearly breast exams for DES Daughters. I had been switched to receiving a mammogram every two years so I took the article to my doctor and was able to receive a mammogram within a week. It took a little fighting with the booking desk and the support of my doctor being willing to go outside the program and order the test as needed now, not in September. Because of the article and the cooperation of my doctor I will be seen every year within the breast screening program because I have now been classified as being at a higher risk for breast cancer. Thank you so much.

—Pat

To the Editor:

I received my copy of DES Action VOICE (issue 123), and it just hit me — that my two DES Daughter sisters and I were all exposed to decades of hormones on top of the initial DES. All of my doctors know I am a DES Daughter yet I was prescribed various birth control pills for upwards of 25 years, simply to regulate my period. Not one of them cared that the pill probably should never be prescribed to DES Daughters who've already had plenty of extra estrogen. My sister with breast cancer underwent numerous IVF cycles so I now wonder if the extra drugs combined with her exposure to cause the disease. I am scared for myself, my sisters and my nieces. I support DES Action's efforts to get word out to doctors who should not prescribe extra hormones to DES Daughters, and I imagine, DES Granddaughters. This is really hitting me hard.

—Deborah

To DES Action:

I am a DES Mother. After three miscarriages, finally an egg and sperm planted itself into a portion of my cleft uterus and now I have a wonderful daughter. Unfortunately, due to the fact that I took DES throughout my pregnancy, during which I was confined to bed for 8 months, my girl was born with no fallopian tubes. She has adopted a wonderful child so finally she is a MOM and I am a Grandmother. A certain amount of guilt survives in me. Her kind and remarkable attitude toward me alleviates some of my pain. I sign my letters to her with an unclosed heart. She scolds me when I do this, but I don't care. I want her to know that I will be sorry forever for having caused her this malformation.

Your readers may find the above a bit excessive, but a fact is a fact and I took the pills. Of course, there will be some DES Mothers who find me wrong, but I'm not. I am angry with the doctors who thought that I needed this medication. (Even chickens are not allowed to eat this stuff anymore).

I am one of the lucky ones due to a terrific daughter like mine. In my mind I had prepared myself for what she might say when I told her once she started menstruating. I decided she would say "I hate you," which is exactly what she said, so I was ready. Later she decided to sue Eli Lilly all by herself. They told her the statute of limitations had run out. What a beautiful excuse… the bastards. They knew in 1962 and kept those advertisements going. If I can help the cause in any way, please include me.

—Margot

Pat Cody's response to Margot:

Reading Margo's letter reminded me how I felt when I first learned about DES and how it could have affected my daughter. We are schooled to take responsibility for our actions. Only later, as I began to find out how the drug companies marketed DES, did I realize it was not my fault, and my dismay turned to anger. The fault lies not with the mothers, but with the drug companies. They are responsible, and we have held them accountable in court, when possible. I shared my anger with others — mothers, daughters and sons — and we moved ahead to build a community of support, education and advocacy. DES VOICE

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"Wonder Drug" Script Reading Tells Hollywood About DES

Nearly 100 film industry insiders and DES-exposed individuals came together for a fun and emotional script reading of Caitlin McCarthy's screenplay about DES.

WONDER DRUG is currently in development with Director Tom Gilroy and Executive Producer Mark Romeo. To the delight of the audience, the script was read by talented actors and actresses: Juliet Landau, John Buffalo Mailer, Kent Osborne, Scott Atkinson, Tegan West, Alicyn Packard, Ruth Williamson and Elizabeth Kate.

The Q&A session opened many eyes and brought some to tears as the story about DES unfolded. DES Daughters Caitlin McCarthy, Elizabeth Kate, Kim Mazeres and Patti Negri fielded questions about DES and its health consequences.

Says DES Action Board Member Patti Negri, "The afternoon was wildly successful in spreading the word about DES!"

Juliet Landau and Caitlin McCarthy

Tegan West, John Buffalo Mailer and Juliet Landau