

Research Sheds Light On How DES Exposure Causes Breast Cancer

*“In Utero Exposure to Diethylstilbestrol (DES) or Bisphenol-A (BPA) Increases EZH2 Expression in the Mammary Gland: An Epigenetic Mechanism Linking Endocrine Disruptors to Breast Cancer,” Taylor, HS, et al, *Hormones & Cancer*, June 2010, a Journal of The Endocrine Society.*

Reviewed by Fran Howell

We have come to understand that DES exposure before birth can set up DES Daughters for an increased risk of breast cancer more than forty years later. Now we have a clearer understanding of the mechanism for why that can happen.

This research confirms, with scientific/biologic results, the epidemiologic findings of the DES Follow-up Study, which shows that DES Daughters over age 40 develop breast cancer at a higher rate than unexposed women.

A team led by Hugh S. Taylor, M.D., professor in the Yale Department of Obstetrics, Gynecology and Reproductive Science, gave DES to pregnant mice and studied their female offspring.

He suspected the drug of interfering with a specific gene-regulating protein and his findings bear that out. DES Daughter mice produced higher than normal levels of EZH2, which plays a part in regulating the functioning

of genes. Scientists recognize that increased EZH2 levels are associated with a greater breast cancer risk in humans.

What Taylor did was identify DES as an endocrine disruptor that alters EZH2 production before birth. He says the alteration continues into adulthood leading to the possibility of increased breast cancer development. He adds, “elevated EZH2 levels caused by DES exposure were found only in breast tissue, not in other parts of the body, and were associated with aggressive forms of disease.”

Taylor makes it clear that DES does not mutate the DNA sequence itself, but rather, changes the regulating system that influences how genes operate,

or turn on and off. His work shows that DES may cause changes in tumor suppressing genes that can lead to breast cancer formation.

The Yale researcher notes that his research confirms, with scientific/biologic results, the epidemiologic findings of the National Cancer Institute DES Follow-up Study, which shows that DES Daughters over age forty develop breast cancer at a higher rate than unexposed women.

BPA Also Implicated in Breast Cancer Risk

In this study, Taylor also exposed a separate group of pregnant mice

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Great News — DES Research Funding Approved for Another Five Years!

By Kari Christianson

It is what we all want. The National Cancer Institute (NCI) has renewed funding of DES research for an additional five years. Dr. Robert Hoover, Director of the NCI's Epidemiology and Biostatistics Program and the DES Follow-up Study, announced the renewed funding at a recent meeting of the DES Steering Committee, which I participated in as the representa-

tive from DES Action USA. The news brought joy and relief to those around the table.

The current funding cycle would have ended in April 2011; this renewed funding commitment from the NCI means the DES Follow-up Study will continue, with participants receiving health questionnaires through 2016! The upcoming round of questionnaires for DES Daughters and DES Sons will be sent

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☐ DES Mother of a: ☐ Daughter ☐ Son

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Join OnLine Support Group for DES Daughters

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

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 Daughter Breast Cancer Cases Combined For Lawsuit

By Fran Howell

Forty-seven DES Daughters have filed suit in U.S. District Court in the District of Columbia seeking damages for breast cancer, which they claim was caused by their prenatal exposure to DES.

According to Washington, DC, Attorney Aaron Levine, the women seek compensation from drug companies that made DES, to cover the costs of their treatment, radiation, surgery, chemotherapy, breast reconstruction and other related expenses.

Levine has assembled a group of experts in the fields of molecular biology, epidemiology, pathology, breast oncology and toxicology. They support the claim that *in utero* DES exposure causes increased anomalies in the developing breast buds. This, he says, “creates a susceptibility to cancer later in life by altering the cytoarchitecture


of the breast bud tissue itself.”

Levine’s experts will tell the court that DES is an estrogen receptor pathway disruptor, binder, and modulator much more powerful than natural estrogen. The rudimentary epithelial ductal tract and fetal bud development of DES Daughters are subject to excessive and untimely proliferation and acceleration during fetal 2nd and 3rd trimester development. That adversely affects cellular regulation leading to increased susceptibility to malignancy.

Levine acknowledges this is difficult litigation because rates of breast cancer rise in all women as they age. “Complicating the case is that there is no unique DES Daughter breast cancer pathological picture, like the signature of clear cell cancer or T-shaped uterus. DES Daughter breast cancers do not look any different under the microscope than anyone else’s,” he says. “However, the fact that DES was

a known carcinogen and known to affect breast tissue and known to cross the placenta since the 1940’s, marketing the drug to pregnant women and their babies was unconscionable and negligent to say the least,” Levine alleges.


It is expected the lawsuit will take at least two years to work its way through the system. Levine’s hope is that case can be certified as a class action lawsuit. Failing that, he intends to pursue each DES Daughter’s breast cancer claim individually. DES Daughters with a breast cancer diagnosis who are interested in learning more about this litigation can contact Levine at either 888-868-5380 or www.aaronlevinelaw.com.

Also, New York Attorney Sybil Shainwald handles DES Daughter breast cancer cases and can be contacted for more information at 212-425-5566 or www.shainwaldlaw.com. 

Research Sheds Light *from page 1*

to bisphenol-A (BPA), another endocrine-disrupting chemical often found in plastics. BPA has estrogenic properties like DES, and in this study also caused increased levels of EZH2 in prenatally exposed adult mice — therefore raising their breast cancer risk.

According to Taylor this study serves to warn that all estrogen exposures before birth, from strong ones like DES to weak ones like BPA, can alter fetal development with dangerous repercussions in adulthood.

He says, “We have demonstrated a novel mechanism by which endocrine-disrupting chemicals regulate developmental programming in the breast,” and adds that DES Daughters should have the annual health screenings they need, “to monitor for the development of breast lesions as adults.” 

DES Research Funding Approved *from page 1*

to participants next year.


Continuation of funding by the NCI for DES research speaks volumes about the importance of following and understanding health impacts of prenatal and generational DES exposure.

This long-term DES research, which follows the health experiences of DES Daughters, Sons, Mothers, and now Granddaughters, was begun in the mid-1970s. All the centers previously doing DES human research were coordinated into the DES Follow-up Study at the NCI in 1992, under the direction of Dr. Hoover.

Among its findings in recent years, the DES Follow-up Study has identified an increased risk for breast cancer and paraovarian cysts in DES Daughters, and delayed

menstrual regularity with possible infertility issues for DES Granddaughters. As research studies are completed during this next cycle, you can depend on the DES Action VOICE to review and explain the results.

DES Action USA thanks the National Cancer Institute, Dr. Hoover and all of the DES Follow-up Study researchers for their dedication and expertise in seeking and identifying health outcomes related to prenatal and generational DES exposure. This research not only serves the goals of the NCI, but also provides needed health information for DES-exposed individuals.

The website for the NCI DES Follow-up Study is www.desfollowupstudy.org and can also be accessed via the link on DES Action’s website under Resources: Online. 

As The Government Studies A Chemical Similar To DES, Consumers Choose Not To Buy It

Environmental Protection Agency announces intensified *scrutiny* as the Food & Drug Administration declares *concerns*, and the National Institutes of Health spends \$30 million to *study* BPA. But Americans don't wait for government action.

By Fran Howell

An infomercial for a kitchen gadget gave me a surprise. Yes, occasionally I am drawn in by those long commercials and this one was for something called the "Ninja." It is a combination blender and chopper with a plastic container. Prominently displayed across the screen was: "BPA-free."

Earlier in the week while shopping and perusing a selection of plastic food storage containers, I noticed several, made by major brands, also proclaimed, "BPA-free."

The government has not banned this endocrine disrupting chemical used to harden plastic, although some states and communities have done so.

Consumers are learning of health concerns and have begun avoiding products made with bisphenol A (BPA). Corporations are

"Individuals are shying away from products made with BPA without waiting for indisputable proof that it is hazardous."

taking notice even though the U.S. government has not forced them to.

We started paying attention to BPA in 1998 when a scientist saw skewed results in an experiment. The non-exposed mice she was studying started showing the same cancers and reproductive problems as the mice she had given DES as part of her study. This unexpected development was caused by BPA leaching from plastic cages after they were thoroughly cleaned with extremely hot water and a strong detergent. The leached BPA affected the health of the mice in the same way DES did. As it turns out, BPA is a synthetic estrogen developed at the same time as DES, only BPA is somewhat less potent than DES.

While the National Institutes of Health began actively studying BPA dangers in 2009 and the Environmental Protection Agency just announced additional scrutiny, consumers have already taken notice. Using the Precautionary Principle — even if they don't

know that is what they are doing — individuals are shying away from products made with BPA without waiting for indisputable proof that it is hazardous.

While the government may eventually regulate BPA, especially in food containers, consumers are acting now by avoiding BPA when possible. The power of the purse is being noticed even as chemical industry executives defend the safety of BPA. Still, many of these same firms that defend BPA are re-tooling their manufacturing processes to produce BPA-free plastics. Power to consumers!

Editor's Note:

A national environmental group has sued the FDA for failing to regulate BPA. Saying, "its patience has run out," the National Resources Defense Council went to court on June 29, 2010. According to NRDC Senior Scientist Sarah Janssen, "Most people assume the government wouldn't allow Americans to be exposed to BPA if it wasn't safe. But while the FDA has been reviewing the science, as of yet, no action has been taken. So we have asked the court to order the FDA to act."

On July 12, 2010 Senator Dianne Feinstein (D-CA) added a provision to the food safety bill, now under consideration in Congress, to ban BPA from the lining of food cans. Both the food and chemical industries have vowed to press for defeat of the measure.

DES VOICE



Annual Cancer Panel Report Shifts Focus To Environmental Dangers

DES Action USA Provided Input Stressing Need For Research

By Fran Howell

Governments are slow to switch course, but we finally may be seeing it happening. Since the 1970s, an annual cancer report has been presented to the President with past ones primarily emphasizing diagnosis, treatment and the need for lifestyle changes to prevent cancer. But this year's report took a different approach. The title sums it up: Reducing Environmental Cancer Risk.

The panel stresses the need for more environmental health studies and takes into account a growing understanding that toxic-exposures before birth can have profound effects on adult health. DES researchers have been leading the way in this area by investigating links between the endocrine disruptor, DES, and cancer. The report spells out clearly the importance of studying such environmental causes of the disease.

Not Polite To Say "I told you so," But We Did!

In our communication with the President's Cancer Panel, DES Action USA told the group, "we have first-hand experience with adverse health effects, including cancer, resulting from prenatal exposure to diethylstilbestrol (DES). Research into exposures to hormonally active substances, like DES, remains critical."

The panel agreed. One of its recommendations is to support large ongoing studies into environmental contaminants with the realization that understanding and regulating

prenatal exposures can result in fewer adult onset cancers later. The DES Follow-up Study is a model for how such research is done well.

The DES Dilemma

DES Daughters are at increased breast cancer risk right now and want the most high tech screenings available for early detection. The panel addresses this with a warning that radiation causes cancer; its effects are cumulative over a lifetime and very underappreciated.

The report stresses the need for lowering radiation dose levels from medical devices through improved technology, stringent inspections and better-trained technicians. Going deeper, the panel even urges notations on patient records of each screening undergone by an individual with the estimated radiation dose received, for better tracking of the accumulated risk.

DES Action USA applauds these suggestions, while knowing implementation is years away. When DES Daughters raise concerns about radiation, we acknowledge they exist, but with the increased breast cancer risk we continue recommending annual mammograms for DES Daughters, beginning at age forty.

Another cancer panel suggestion that we wholeheartedly support would have health care providers routinely ask patients about previous and current environmental exposures at work and home. That would make it much easier for the DES-exposed to "tell their doctors."

We Know Enough To Act

DES Action USA subscribes to what's known as the "precautionary principle," which calls for action to protect public health when there is credible evidence of harm – rather than wait for absolute proof before acting.

The 2008-2009 President's Cancer Panel has come to the same understanding, noting that while there is much left to study, "in a great many instances, we know enough to act." This move toward a precautionary approach to cancer — rather than reacting after the fact — is refreshing.

We are also pleased with the Panel's recommendations of giving manufacturers the burden of proving chemical and drug safety prior to a new chemical or drug approval, and then mandating subsequent post-marketing safety studies as well.

A Turning Point

The Panel's recognition of the importance of mitigating environmental cancer causes is a welcome change from previous reports with their singular focus on diagnosis and treatment. The report concludes with the admonition that our government should listen to environmental and health advocates when developing cancer research and regulatory agendas. DES Action USA will continue providing input with the feeling that perhaps now, some in Washington are listening more intently.

 **DES VOICE**

Here's Your Chance To Participate In Research Studies

The Army Of Women and the Health Of Women (HOW) Studies Are Both Recruiting New Participants

By Kari Christianson

DES Action is often asked if there's any way to participate in research about DES. Until now, unless you were already part of the National Cancer Institute DES Follow-up Study, there was no way to share your DES experience with researchers. But now you can.

While not specifically about DES exposure or for DES-exposed individuals, both the Army of Women and the Health of Women (HOW) Studies are seeking participants.

The Army of Women, a project of the Dr. Susan Love Research



Foundation and with support from the Avon Foundation, is seeking to enroll a million women in order to learn more about the causes of breast cancer. Dr. Love understands that environmental exposures like prenatal and generational DES exposure must be examined as part of this effort. At present more than 335,000 women have joined the effort, meaning they've gone to the website to enroll (www.armyofwomen.org).

All women are welcome to sign up, whether or not they have had breast cancer. Information about research studies arrives via e-mail.

According to the website: *"There are many different types of studies. Some might require you to complete a questionnaire, while others might need a sample of blood, urine, saliva, breast fluid, or breast tissue. Some studies might be clinical trials testing a new detection marker or drug. You decide which studies you want to take part in."*

Then, *"If you fit the criteria and you'd like to participate, all you need to do is RSVP and let us know you've accepted our*

"Call to Action." You will be asked to go through an online screening process to confirm you fit the criteria for the study."

Finally, the Army of Women website stresses that, *"You are in complete control and you select what you want to do! You will never be pressured to take part in any study. The decision to take part is yours — and yours alone."*

Breast cancer research is taking place at universities around the country. This is one good way of getting involved. Scientists are looking for participants who are eager to help. By forming the Army of Women, Dr. Susan Love wants to connect researchers and women, so that together they can accelerate studies into the causes of breast cancer.

Health of Women (HOW) Study

Some women who registered for the Army of Women have not received a Call-to-Action for a study that was right for them. So a new initiative is being launched to gather information from anyone who wants to provide it for research purposes.

Developed under the auspices of the Army of Women and the National Cancer Institute (NCI), the Health of Women (HOW) Study is creating a group that can be followed over time. Health data will be collected for analysis to identify common breast cancer risk factors. Anyone with a desire to help with breast cancer research can participate, whether they've been diagnosed with the disease, or not. **Individuals who have not had breast cancer are needed as a control group.**

Every few months a set of questions will be asked regarding your health history, diagnosed cancers, and reproductive health. No need to leave your house to help. The HOW study is handled strictly online.

When you enroll in the Army of Women you'll receive information about signing up specifically for the HOW Study, too.

The Army of Women and the HOW Study will create the first large online breast cancer research cohort, with the goal of a million women.

According to National Cancer Institute Director Dr. John Niederhuber, "This program will be able to securely manage massive amounts of clinical and demographic data, harnessing the enthusiasm of women around the globe to participate in research."

Hopes are high within the NCI and the Army of Women that access to so many women (and a few good men who have had breast cancer and signed up for the HOW Study) will change the course of cancer research and treatment through a better understanding of what causes the disease.

Don't Forget to Mention DES!

You will notice the basic Army of Women enrollment questionnaire does not specifically ask about DES. No problem. This basic sign-up simply provides access to a variety of breast cancer studies that need participants.

When you qualify for a study, and decide to register for it, you will then be asked additional questions. This more in-depth questionnaire is where you should identify yourself as DES-exposed. Hopefully enough DES Mothers, Daughters, and Granddaughters will participate to be noticed. This is your chance to make a difference!

The mission of the Army of Women is, "One million women. One research goal. One revolutionary opportunity. Together we can prevent breast cancer."

To learn more, go to www.armyofwomen.org.

DES VOICE

Tricky Hormone Subject Tackled With Wit and Interesting Insights

Engaging And Well-Written Book Penned By DES Action USA Member

Safe Hormones Smart Women, by D. Lindsey Berkson, iUniverse, Inc., 2010, \$22.95.

By Kari Christianson

The words “safe hormones” in the title read like an oxymoron for DES-exposed women. But Lindsey Berkson offers a witty and understandable explanation of the endocrine system, hormone replacement options and healthy living. While coming down firmly on the side of using bioidentical hormones, she just as solidly states that all decisions about hormone balance and replacement should be made with a health care practitioner. Every woman has to determine what’s right for her health and her peace of mind.

A long-time advocate of understanding how estrogen and all hormones affect a woman’s body, Berkson, a DES Daughter, isn’t just riding the wave of Oprah’s endorsement of bioidentical hormones. This is Berkson’s fourth book on women’s health, hormones, understanding estrogen and bioidentical hormones. Berkson presents her point of view and health information in a savvy and easy to read style.

Whether or not you are interested in (or agree with) everything in Berkson’s book, I found it packed with details on how the female body works with and utilizes hormones. There are helpful explanations about tests for hormone levels, definitions of natural, synthetic and bioidentical hormones, and terrific nutritional hints for all women, whether or not they are using or thinking about hormone replacement.

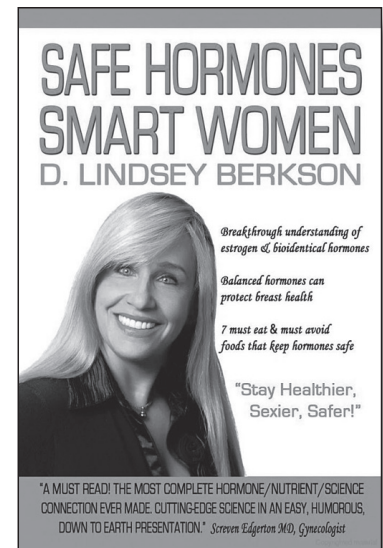
This book is not written specifi-

cally for a DES-exposed woman; in fact, DES exposure is not mentioned in the book. However, as a DES Daughter who is at peace with my decision to go without any hormone replacement during menopause, I recognize that it’s important to have information about all options available for women. And I also recognize, just like Berkson, that each woman must make decisions about hormone replacement based on her health history and in consultation with her health care provider.

Berkson, a nutritionist, has been in clinical practice for many years, and is a participating scholar at the Center of Bioenvironmental Research at Tulane and Xavier Universities. More information about D. Lindsey Berkson and

her books can be found at www.lindseyberkson.com.

DES VOICE



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FINDING BOOKS THAT MATTER TO US

By Pat Cody

We often get questions on the availability of books that were either written about DES exposure or reference it. Some are now out of print and no longer available in bookstores. If your library can't help, there is still a way to get them.

The website www.abebooks.com is a consortium of thousands of used bookstores whose catalogs are on-line. You write in the author and title, then click "find the book" and you get a listing of copies that are available, starting with the least expensive. To purchase, click on "add to cart" and then "proceed to check-out."

Here are some books of lasting value to the DES community, with prices, including shipping, we found on the abebooks website:

Cynthia Laitman

"DES: The Complete Story" \$3.99

Barbara Seaman

"Women and the Crisis in Sex Hormones" \$3.62

Joyce Bichler

"DES Daughter" \$3.64

Diana Barbara Dutton

"Worse than the Disease: Pitfalls of Medical Progress" \$3.63

Theo Colborn

"Our Stolen Future" \$5.04

Margaret Braun

"DES Stories" \$3.62

Ruth Ozeki

"My Year of Meats" (a novel) \$3.64

Judith Turiel

"Beyond Second Opinion:
Making Decisions about Fertility Treatment" \$3.64

D. Lindsey Berkson

"Hormone Deception" \$4.73