DES Action® VOICE

Inside

A Focus On Diethylstilbestrol

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New Study Finds No Differences in Blood DNA Methylation Among DES-Exposed

By Virginia Pelley

A family health history that includes DES exposure can create a lot of anxiety about the unknown: How will it affect your health, and—more to the point—will DES exposure raise your risk of disease? A new study published in in the journal *PLOS One* in March brings us another step closer to answering those questions.

The study compared DNA methylation in DES-exposed women vs. a control group of women with no DES exposure.

"DNA methylation is a normal process that helps control which genes are turned off or on in different tissues," explains co-author Jack A. Taylor, MD, Ph.D., head of the Molecular & Genetic Epidemiology Group and Epigenetic and Stem Cell Biology Laboratory at the National Institute of Environmental Health Sciences (NIEHS). "If that methylation pattern gets altered by exposure or other outside factors [such as DES], it *might* alter which genes are off (or on) and affect your risk of developing different diseases."

Cancer cells, for example, have major alterations in DNA methylation, but this pattern of alteration varies from tumor to tumor, Dr. Taylor says.

This NIEHS study compared the blood of 100 DES-exposed, non-Hispanic white women 40-to-59 years old from the Sister Study—a large cohort study of women with a family history of breast cancer—with a control group of 100 women who didn't have a history of DES usage in their families.

Researchers hypothesized that subjects who were exposed to DES in utero would show detectable changes in their blood, and that those changes were partly responsible for the increased risk of infertility and some cancers in the children of mothers who took DES while pregnant.

Several studies with mouse subjects have found lasting differences in DNA methylation between mice exposed to DES *in utero* and mice in unexposed control groups, so the results of this study are a little surprising: Researchers found that "Adult women exposed to DES *in utero* had no evidence of large persistent changes in blood DNA methylation," they wrote.

Dr. Taylor cautions that the results of this study shouldn't be interpreted

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The DES Legacy

Endocrine disruptors similar to Diethylstilbestrol (DES) are everywhere in our environment, but how harmful are they really? Top experts in the field distill the reams of new information about hormone-disrupting chemicals such as BPA.

By Virginia Pelley

Almost daily, a story hits the news linking health problems to our exposure to hormone-disrupting chemicals similar to DES. The current poster child for endocrine disruptors is bisphenol A or BPA, a synthetic chemical found in the linings of some cans, plastic bottles, some cash register receipts and many plastics. Experts note, however, that there are countless other less-studied chemicals that we're also exposed to, and that are little understood.

In "State of the Science of Endocrine Disrupting Chemicals," the report the United Nations Environment Programme and World Health Organization released in 2012, scientists worldwide expressed concern that many endocrine-disrupting diseases and disorders are on the rise, and that "only a small fraction of [the 800 known or suspected endocrine-disrupting] chemicals have been investigated."

But how much of this new information is theoretical at this point, and how much suggests serious risks to our health? Outside of the scientific community, few people have a deeper grasp of the risks and effects of endocrine disruptors than those who have been exposed to DES. Even so, keeping up with the information scientists have gleaned from the ever-growing number of studies published about hormone-disrupting chemicals can prove difficult. To help distill pertinent information about the latest research about these chemicals, such as BPA, we asked three top experts who study endocrine disruption to share their insights with us:

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- **VOICE Newsletter**—current and historical. The VOICE is the most popular member benefit of DES Action. Now access all 36 years of newsletters and search for any topics or articles you need. The VOICE documents the history, the science and the personal stories of DES and all of us who were exposed.
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Here is a safe place for discussing very personal issues that arise for DES Daughters. We live in the farthest reaches of the country but have developed a sense of community together, via our email listserv.

What we talk about is private—just between us—so we can feel free to raise questions on topics we aren't comfortable bringing up with others. What is amazing is the depth of knowledge in the responses.

It's a terrific resource for information and support from DES Daughters who wrestle with the effects of menopause, family relationships and medical diagnosis issues specific to DES exposure. To join the support group, send an email to:

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THE MISSION OF DES ACTION USA IS TO IDENTIFY, EDUCATE, EMPOWER AND ADVOCATE FOR DES-EXPOSED INDIVIDUALS.

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Bood DNA Methylation

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as a negation of previous studies that found changes in DNA methylation that appeared to be tied to prenatal DES exposure.

"A study like ours, which did not find evidence of an association, is best interpreted narrowly," he says. "There are many possible reasons why there could be associations found in animal studies that are not seen in our study: different species, much longer time between exposure and measurement, different dose or different tissue than [used in] the animal studies."

It's still unclear to what degree outside forces might alter methylation patterns and lead to disease, Dr. Taylor continues.

"We and many others are trying to investigate whether methylation patterns are associated with exposure and disease, which was the underlying rationale for this study," he says. "We've already published findings about methylation in relation to aging, smoking and breast cancer risk (each of which showed associations), but found no association with DES." DES VOICE

DES Legacy

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DES Action: Patricia, you just published a study in PLOS Genetics that found lower sperm counts in subjects exposed to BPA and also permanent alterations in the functioning of the stem cells responsible for producing sperm.

Patricia Hunt: There was certainly some evidence of an association between exposure to hormone-disrupting chemicals and decreased sperm counts and infertility out there already; several Danish studies conclude that sperm counts in young Danes are dropping. Importantly, the change has been over the course of one generation. Danish scientists came up with the idea that maybe it was estrogenic exposures, and animal studies have borne this out.

Males produce sperm continually. A small population of stem cells slowly divides and sends new cells off to make sperm, which means sperm production is continuous. What we found is that BPA exposure is affecting that stem cell—and the subtle changes to that cell alter the way the testis makes sperm. The end result is an increase in errors during the process, and these errors result in a dead sperm cell rather than a live cell. So this gives us new insight into why sperm counts are dropping. We're not saying this is the only way exposure to endocrine-disrupting chemicals affects the testis, but it's providing us new insight about why sperm counts could be dropping.

Sex determination—occurs early in pregnancy—at eight weeks in humans. Testes develop slowly throughout pregnancy and after birth and don't mature until the male reaches sexual maturation. The stem cell population is developing as the testis develops, and our studies indicate that this is a critical period during which exposures can have an impact.

What we're most interested in now is determining the extent of that critical window of development. We need to understand when this set of stem cells is being set aside, and whether these stem cells remain vulnerable throughout life. Would we see the same effects in an adult? We haven't had time to answer those questions yet.

There has been some argument recently between scientists about what level of exposure to BPA is enough to result in negative health effects. As I'm sure you've heard, the European Food Safety Authority (EFSA) just issued a statement in January that common BPA exposure levels don't pose a health risk to humans. (www.efsa.europa.eu/en/press/news/150121.htm) What is your opinion about that, the claim that BPA exposure levels from environmental sources such as food packaging, beauty products and receipts aren't significant enough to cause harm?

Shanna Swan: This is a highly politicized question with large economic implications. BPA is definitely an important exposure, but perhaps overemphasized given the huge number of chemicals to which we are exposed. However, there are now hundreds of peer-reviewed, well-done studies demonstrating significant health effects of BPA. While the science will continue to emerge, there is sufficient evidence to take precautionary action, particularly during pregnancy.

Retha Newbold: The most important thing about endocrine disruptors, whether it's DES or BPA or others, is developmental exposure. Both DES and BPA have been linked to developmental exposure causing problems. I'm not saying adult exposure isn't important, but there's a lot of gene programming that's going on in fetuses, babies and children. The programs are being set, how a tissue responds to a stress, how it responds to estrogens later on, how genes are turned on and off—all of that is set up in prenatal and neonatal life, during development. So exposure to any endocrine disruptor can alter the programming.

Perhaps the person doesn't see BPA for rest of their lives, but that short

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Patricia Hunt, Ph.D., is a geneticist, BPA expert and Meyer Distinguished Professor at the School of Molecular Biosciences at Washington State University.

Shanna H. Swan, Ph.D., is a professor of preventative medicine at Icahn School of Medicine at Mount Sinai in New York City and an expert on the impact of environmental exposures on male and female reproductive health.

Retha Newbold, M.S. is a researcher emeritus at the National Institutes of Environmental Health Sciences (NIEHS) in North Carolina who has published numerous studies on diethylstilbestrol (DES) and other endocrine-disrupting chemicals.

exposure time during development means that person could end up with cancer later on. The whole concept of early exposure having long-term effects, the attention drawn to it is due to DES. That's the other thing that they have in common: problems with developmental exposure that can cause long-lasting effects. And it doesn't have to be mega amounts of developmental exposure to cause damage.

I think the jury is still out on whether BPA is safe at current exposure levels. This is why I am working with the National Toxicology Program here at NIEHS in collaboration with the FDA in a consortium-based research program with 12 NIEHS extramural grantees to link data together to determine if BPA is safe. This program is called CLARITY- BPA (Schug et al.2013), and papers from this collaboration will be published starting this spring.

PH: Our hypothesis [for our study] came from studies in humans that were subsequently supported by studies in rodents. I always use DES as an example, in my field, when people say, "Well, we've only seen this in rodents, so we don't know what the effect would be in humans." I point out no, we ran the DES experiments in humans first, and we, humans, turned out to be a terrific model for studies of the mouse! The DES effects seen in rodent studies, we saw first in humans. So I never like to see that DES experience dismissed because it provides such compelling evidence echoing what we're seeing in rodent studies of endocrine disruptors.

Some critics of a few of the newest studies refute the significance of the findings because they say that the amounts of BPA subjects were exposed to in them was too small to reflect the amount people are actually exposed to in everyday life.

PH: The party line is that the levels animals are exposed to in some of these studies are 1,000 times higher than everyday human exposure levels. But no one knows how much BPA people are actually exposed to. My colleagues and I have tried to set our doses at levels that are relevant to humans, and the only way we can gauge that is by looking at what's in human blood and then trying to mimic those levels in mouse studies. Our doses were calibrated to provide levels in circulating blood that are comparable to humans. So I think that's a lame argument.

I get kind of tired of this constant battle in the BPA world. BPA is a poster child for a lot of chemicals that are bad actors because our bodies perceive them as hormone-like substances or because they interfere with our bodies' hormones. But what I'm more concerned about is that there are a lot of chemicals out there, and I don't care if it's BPA or BPS or whatever, if they have endocrine-disruptor properties, I'm really concerned about them getting into our bodies, particularly in developing fetuses and newborns.

What is BPS, and is it safer than BPA? What should we know about products that are supposedly "BPA-free" or labeled that they contain BPS and not BPA?

RN: Bisphenol S (BPS) is an analog or similar chemical to BPA that's being used in place of BPA. I was at a meeting yesterday discussing five different BPA analogs; unfortunately, we know less about them than we do about BPA. There's nothing to suggest any of these are any safer than BPA. The ones I saw yesterday looked identical to BPA, and I don't feel any safer using them than BPA. The general public doesn't know this, but they're picking up on it fast. People are more skeptical than they used to be, and it's a good thing.

In their report, the United Nations and WHO said, "Understanding the effects of the mixtures of chemicals to which humans and wildlife are exposed is increasingly important." But despite growing concern, mixtures are barely being studied. Do you agree?

SS: Mixtures of chemicals (as well as chemicals mixed with pharmaceuticals and other factors, such as stress) must be studied. We need to study human-relevant scenarios, and pregnant women are exposed simultaneously to all of these. This is of the highest priority.

We're just starting to look at mixtures as a whole. The magic number that most everyone quotes is 80,000 chemicals in commercial use today. Maybe 2,000 have been adequately studied, but we haven't studied how they interact at all. The other thing is that these chemicals are in use but we don't know where; chemical companies don't have to say where they are or where they're going. Until we started studying BPA, we had no idea that it was everywhere.

Studying mixing is not something the chemical companies are going to do on their own. It's going to have to be done by academic scientists and by the federal government. And there's actually funding for that, but the topic is very new on the radar.

What do you think needs to be done?

PH: A huge issue for me is the way we conduct risk assessments of chemicals—it's just not good enough for me. These things go into production and creep into our lives, acting like hormones or interfering with hormones, and we know that it doesn't take very much of these chemicals to have an impact on animals and humans. The industry argues that it's all about levels, levels, but it's not about the level of exposure with these types of chemicals. They can assert powerful effects at extremely low levels.

What we really need is new types of chemical testing before they go on the market. The EU is going through this debate right now and trying to decide how much they need to tighten up. I'd like to see the same thing happen here. Consumers often assume, "Well, if it was really bad, the EPA and FDA would be all over this." But the bottom line is, the onus is not on the industry to show that it's safe, it's on the government to prove it's *not* safe and should be taken off the market. And that's just plain silly.

Regulators are comfortable evaluating the results of traditional toxicity tests, but those types of evaluations don't work well for these types of chemicals. When risk evaluations are done, it's easy for evaluators to understand a big industry study, but when they see a bunch of smaller studies, like ours, they don't understand the endpoints or how to interpret results.

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We simply need to develop new ways of testing and adequately test chemicals *before* they enter our lives.

How can consumers make a difference in reducing our chemical exposure?

RN: As for BPA, I tell people that until we have additional information, I would suggest not heating items in plastic in the microwave because we know that heating releases more BPA into food. Eliminate any exposure you can think of to BPA while you're pregnant. I wouldn't give kids plastic toys that have BPA or phthalates in them and would say generally to avoid as much BPA as you can. Some studies say there's BPA in thermal paper, so have receipts sent electronically and certainly, don't rub your hands on them.

PH: Raising consumer awareness is a big part of the game here; consumers can make better choices if they're informed. They can ask for what they want and can get it. The choices consumers make drive the products that appear in the marketplace. DES VOICE

Update: Drug Company Reapplies for FDA Approval of 'Pink Viagra'

By Virginia Pelley

You may have caught wind of the aggressive campaign to promote flibanserin, a drug purported to treat low libido in women. Sprout Pharmaceuticals, the company seeking approval of the drug, says flibanserin will treat "Hypoactive Sexual Desire Disorder," which they define as "persistent or recurrent deficiency or absence of sexual fantasies and desire for sexual activity that causes marked distress or interpersonal difficulty." But as former DES Action program director and MedShadow Foundation board member Kari Christianson pointed out in the last issue of the VOICE, hypoactive sexual desire disorder isn't a recognized medical disorder. And critics say that the promotion of flibanserin as a "women's rights" issue (see Womendeserve.com and Eventhescore.com) is misleading at best, and dangerous at worst.

In a Feb. 27, 2015 op-ed for *The New York Times*, sex educator Emily Nogoski wrote: "The biggest problem with the drug—and with the FDA's consideration of it—is that its backers are attempting to treat something that isn't a disease." Ellen Laan and Leonore Tiefer, in a *Los Angeles Times* op-ed in which they call flibanserin the "sham drug of the year," wrote, "In study after study, women's response to both test medications and placebo drugs is high. These repeated findings do not support the 'unmet medical need' theory."

Originally developed by a German pharmaceutical company as an antidepressant, flibanserin—said to increase levels of dopamine and decrease serotonin (which can hinder sex drive) in the body—was rejected for that purpose by the FDA in 2010. Sprout acquired flibanserin in 2011 and has since sought FDA approval for its use as a fix for flagging libido, after some women in early trials reported that they felt more interested in sex after using the drug.

Women who participated in studies of flibanserin also reported side effects including drowsiness and dizziness, and as of yet, Sprout hasn't been able to show that using flibanserin won't interfere with serotonin-affecting antidepressants such as Zoloft.

Reporter Rob Stein explained a major element of the concern about flibanserin in a story for NPR: "On a biological level, men and women function very differently when it comes to sexual arousal and performance. Viagra—and medication like it—is all about the plumbing. Men who get aroused but fail to get erections take the pill when they want to have sex, and it increases blood flow to the penis. That is far simpler and more direct than a treatment like flibanserin, which is trying to change how women's brains are wired and must be taken every day."

Christianson submitted a letter to the FDA (read it in full in the last VOICE) strongly urging the agency to reject Sprout's last application, writing: "As a population already harmed by a FDA-approved drug, we wonder if political and media attention is the reason for considering and reconsidering drugs for any female health or disorder issue, rather than attention to safety and efficacy."

So far, the FDA appears to agree, saying that Sprout has failed to show that the risks and side effects of flibanserin don't outweigh unimpressive evidence that it could boost libido. Although its latest application was rejected, Sprout remains undeterred: The company resubmitted its approval request and is reportedly confident that new information about driving safety while taking the drug and lack of SSRI interference will convince the FDA to give the go-ahead to the drug.

Female sexuality is complex. Women who want one of course deserve an effective remedy for flagging sex drive. But any drug that interacts with as many bodily systems as flibanserin must be proved safe without question and more than just "possibly" effective before it's approved for use.

We hope the FDA again listens to the legitimate concerns raised by sex educators and women's advocates that we don't need another inadequately tested medication to "treat" a disorder that doesn't actually exist. As Christianson also pointed out in her letter to the FDA: "DES Daughters are living proof that good intentions and poor research lead to disaster, potentially for generations to come." We'll keep you posted about developments. DES VOICE

Are Mammograms Useless for DES-Exposed Women?

Your best plan for optimum breast cancer screening

By Virginia Pelley

We know that DES-exposed women are at higher risk for breast cancer in their 40s and 50s (cancer rates even out with the general population when women reach their 60s), so early and adequate screening for the disease among this population is particularly important. Because women with DES usage in their health histories tend to have breast tissue that's denser than average, some are concerned that a regular mammogram is an inadequate breast cancer screening method for them. And if your doctor sees a suspicious lump and sends you for an ultrasound as a follow-up, you might wonder if you should maybe skip the mammogram if an ultrasound would be a more effective screen. But that's probably not a good idea, experts say. Here, doctors explain the importance of mammography and give their advice for your most effective screening methods.

DES mothers and daughters who know they were exposed are usually aware that they need to screen more carefully and more often for breast cancer. Therefore, some women in the community have expressed concern that they're exposing themselves to dangerous amounts of radiation during mammograms.

Their fears are unfounded, however, according to Gary Levine, MD, medical director of several MemorialCare Breast Centers in Southern California and president of the National Consortium of Breast Centers.

"The amount of radiation a patient is exposed to from a mammogram is extremely low," Dr. Levine says. "The associated risk has been well-studied and is felt to be negligible. A simple analogy: The amount of radiation exposure from a routine mammogram is comparable to that from flying from Los Angeles to New York City."

And if you worry you're wasting your time getting mammograms, don't.

"Even for dense breasts, despite decreased mammographic sensitivity, mammography is the only screening test demonstrated to save lives using the most rigorous scientific testing available," says Zeynep Yilmaz-Saab, MD, board-certified radiologist at Barbara Ann Karmanos Cancer Institute in Detroit.

"In both randomized clinical trials and population-based observational trials, mammography has been shown to reduce breast cancer mortality by up to 40 percent in women who have actually undergone regular mammographic screening," Dr. Levine adds.

If he or she doesn't suggest it, you might want to ask your doctor about digital tomosynthesis, a low-dose X-ray that shows radiologists more contrast between normal and abnormal breast cells, making the detection of small cancers easier.

"Women with dense breast tissue should begin their screening with 'digital tomosynthesis,' aka, '3D mammography,' a new iteration of mammography that was specifically developed for women with dense breast tissue," notes Dr. Levine.

"Clinical studies have shown a 28 percent increase in breast cancer detection and a 42 percent increase in invasive breast cancer detection when compared to conventional 2D mammography," Dr. Levine says.

Additional Screening Options

In addition to 3D mammography, supplemental screening test options include Magnetic Resonance Imaging (MRI) and ultrasound, also called sonography.

Breast MRI screening uses strong magnetic fields and radio waves to produce images of the body without the high-energy radiation produced by an X-ray. It is recommended only for women with a high risk of breast cancer. It's generally considered more sensitive than a mammogram, but it can miss some cancers that a mammogram will detect. In addition, there's a high rate of false positive results and breast MRIs are very expensive.

Whole breast ultrasound screening should always be used as an adjunct to mammography, not as a replacement, says Dr. Levine, echoing the recommendation of the American Cancer Society.

"Ultrasound is valuable specifically for additional screening of women with dense breasts in whom the sensitivity of conventional mammography suffers, as the dense breast tissue can mask a cancer or mimic a cancer when none exists," Dr. Levine explains. "Studies have shown that the use of adjunctive ultrasound screening in women with dense breasts will allow the detection of approximately 3 additional cancers per 1,000 women screened on top of the 5 found by mammography."

There are two types of supplemental screening breast ultrasounds: one done via a handheld device with which radiologists scan the whole breast and automated breast ultrasound technique, in which a machine scans the breast. This test is not limited by tissue density, doesn't use radiation, is well-tolerated by patients and is inexpensive, according to Dr. Yilmaz-Saab. While false positives can be high with ultrasounds, "Small studies have shown a slight increase in cancer yield," she adds.

Dr. Levine and Dr. Yilmaz-Saab agree that the best breast cancer prevention plan starts with a thorough discussion with your physician about your health history.

"Breast density alone has a small impact on breast cancer risk, and there are no uniformly accepted guidelines on additional testing," notes Dr. Yilmaz-Saab. "Clinicians can elicit risk factors (such as a DES history, BRCA-positivity or a history of prior chest irradiation) and evaluate patients accordingly."

Don't be afraid to speak up and ask questions so you and your healthcare provider can determine which breast screening methods are best for you.

DES VOICE

New Chemical Regulation Bill's Value in Doubt

By Virginia Pelley

Everyday chemical exposure is linked to an increasing number of serious health concerns, including asthma, early puberty, infertility and obesity. As our expert panel in "The DES Legacy" pointed out, tighter restrictions on the usage of these thousands of inadequately tested chemicals is of crucial importance to our health. But a new bipartisan Congressional bill addressing chemical safety for consumers introduced in March isn't generating rave reviews from many Democrats and environmental advocates. In fact, they warn that this bill makes matters worse by watering down the weak EPA regulations of chemicals already in place.

U.S. Senators Tom Udall (D-N.M.) and David Vitter (R-La.) introduced the bill, titled "The Frank R. Lautenberg Chemical Safety for the 21st Century" in early March, calling it the new version of the Chemical Safety Improvement Act that the late Sen. Lautenberg introduced in 2013. This bill has been debated and negotiated (but not passed) for the last two years.

Although the late senator's bill was supported by many environmental nonprofit organizations, the Udall-Vitter proposal has generated more enmity than enthusiasm among them. Scott Farber, vice president of government affairs for the Environmental Working Group, explained one of the major concerns about this new bill in a story on Ewg.org in March: "Simply put, this new industry-supported bill would fail to ensure that chemicals are safe, fail to set meaningful deadlines for safety reviews, fail to provide EPA with adequate resources and deny states the ability to protect public health and the environment."

Farber's description of the bill as "industry-sponsored" isn't a trumped-up accusation. According to *The Houston Chronicle*, the draft bill, which was circulated as a Word document, shows that the "company" where the document originated is the American Chemical Council; this information was found by clicking on "advanced properties" in Word.

Sen. Barbara Boxer (D-Calif.) told the paper, "Call me old-fashioned, but a bill to protect the public from harmful chemicals should not be written by chemical industry lobbyists. The voices of our families must not be drowned out by the very industry whose documented harmful impacts must be addressed, or the whole exercise is a sham."

Huffington Post reporter Lynn Peeples outlined the problematic pieces of the bill regarding years-long deadlines: "Under the Vitter-Udall bill, once the U.S. Environmental Protection Agency begins assessing a chemical deemed 'high priority' due to its suspected toxicity, states are barred from imposing new restrictions on that chemical for the same uses the EPA is investigating. Existing state laws, enacted before Jan. 1, 2015, would be allowed to stand."

Peeples quoted Mike Belliveau, executive director of the Environmental Health Strategies Center, about how long this process with the EPA could take: "Under the bill, for a chemical that everyone agrees is unsafe, states can't act, even when EPA is not acting. … It's the best of both worlds for the toxic chemical industry—the bill blocks state action, while slow-walking EPA through endless delay tactics," Belliveau said.

The EWG's Farber further breaks down how the lax deadlines in the bill would play out:

"The EPA estimates that roughly 1,000 chemicals need immediate health and safety review. Under the industry bill, that process would take hundreds of years. It would require only that EPA start reviews of 25 chemicals within 5 years and would allow the agency up to 7 years to review each substance. There is no deadline for implementing restrictions, phase-outs or bans of even the most toxic chemicals, which in many cases have contaminated Americans' blood for decades."

Sen. Boxer and Sen. Edward Markey (D-Mass.) have introduced an alternative to the bill that would place much more stringent requirements on chemical companies and impose tighter deadlines for EPA actions.

The EPA estimates that roughly 1,000 chemicals need immediate health and safety review. Under the industry bill, that process would take hundreds of years.

However, some political pundits say that they have little confidence that the Boxer-Markey will pass without bipartisan support. Both the EWG and National Resources Defense Council issued statements supporting it.

For more information about the shortcomings of the proposed bill and the alternative initiative,visit Ewg.org/take-action to voice your concern regarding this important environmental/health issue. DES VOICE

We Want to Hear From You!

As important members of the DES community, your opinions matter to us, so we would love your feedback. Tell us which articles you liked, didn't like and what topics you would like to see covered in future issues of the VOICE. Email VOICE editor, Virginia Pelley, at Virginia@desaction.org, or share your ideas and questions on our Facebook page or on Twitter: @DESActionUSA.

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New Memoir by Author and DES Daughter Alice Eve Cohen

We're excited to announce the release of a new book by DES daughter Alice Eve Cohen, author of the award-winning memoir *What I Thought I Knew.* In her new book, *The Year My Mother Came Back,* Cohen's mother "returns" 30 years after her death during the most challenging and frightening year of Cohen's life. This re-examining of her relationship with her mother and reflection about her own childhood ultimately showhelp Cohen become a better mother to her own kids.

"I'm eager to share my memoir with VOICE readers, and with the whole DES community," Cohen says. "My own DES history, woven through the book, has affected three generations of mothers and daughters in my family: My mother (who had breast cancer, possibly DES-related), my two daughters (one adopted, one biological) and me.

"I first found out about DES in the 1970s, when I was in college. It caused such terrible strife in my relationship with my mother, who had wanted to keep it a secret from me. She died when I was 22, before we were able to repair our relationship. Now that I'm 60 years old and a mother myself, I'm finally able to understand my own mother with greater empathy and compassion. Her wish to keep my DES exposure a secret from me, though misguided, was motivated by love. My two daughters continue to be affected by my DES exposure, in ways that I could never have predicted. As the DES-exposed community gets older, it's important not to let our story be forgotten."

Look for an excerpt of *The Year My Mother Came Back* in the next issue of the VOICE and for more info, visit AliceEveCohen.com.