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A Focus On Diethylstilbestrol

FALL 2017 #154

DES Action Urges Task Force to Highlight DES Exposure in Cervical Cancer Screening Recommendations

The US Preventive Services Task Force (USPSTF) proposed new national recommendations for cervical cancer screening in early September. Their draft recommendations suggest that women ages 30 to 65 receive either cytology (a Pap test) every three years or a high-risk HPV test every five years instead of the current recommendation to receive co-testing (cytology and an HPV test) every five years.

Except—once again—their recommendations don't make it clear enough that DES Daughters are exceptions to these recommendations. Because of the higher risk of cancer caused by DES exposure, DES Daughters should get more frequent screenings, and they need to be sure their doctors know that too.

Reliable cervical cancer screening recommendations for DES Daughters do not exist because too little research exists to formulate specific, evidence-based recommendations for them (much less DES Granddaughters). Therefore newly proposed USPSTF guidance, like current recommendations from two dozen organizations, does not apply to those exposed to DES.

The USPSTF—an independent panel of experts who do not receive any payment to review evidence and develop preventive policy recommendations—has a public

comment period before officially adopting its recommendations. During the public comment period, which ended on October 13, DES Action Executive Director Su Robotti and Community Manager Karen Calechman submitted a statement to the USPSTF. The full statement is on the DES website; here are the key parts:

“As the Executive Director of and the Community Manager of DES Action USA, and as DES Daughters, we note that the few portions of the population that are not included in this recommendation are summarized in fewer than three lines.

“We urgently request that the identification of higher-risk populations be included in the primary recommendations so that clinicians know immediately who is a higher risk and therefore will

click to ‘Clinical Considerations.’

“This recommendation statement does not apply to women who have been diagnosed with a high-grade precancerous cervical lesion or cervical cancer, and women with in utero exposure to diethylstilbestrol.

“It would also be prudent to add within Clinical Considerations that this population needs to discuss their risks with their physician, as their risk may be higher and they may need more frequent screening.”

Clinicians need to prominently see the populations that are exceptions to the recommended guidelines. The DES-exposed community is one of the highest-risk populations in the US. DES Action USA hopes the USPSTF, a federal body that creates policy for the entire US population, will make it clearer which populations are at higher risk.

DES VOICE

Endocrine-Disrupting Chemicals May Contribute to Obesity

A growing body of research is beginning to link obesity and human exposure to synthetic compounds, such as DES, that interfere with the human endocrine system. The endocrine system regulates metabolism and controls hormone distribution in the body. It acts like a massive transportation system, with

cars and trains zipping through the body from one organ to another carrying instructions for functions the body needs to carry out.

Sex hormones such as testosterone and estrogen, for example, tell the body to carry out reproductive and other

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JOIN THE CONVERSATION

New Member Benefits!

Part of our upgrade to the DES Action USA website includes a new members-only area. As a member, you'll be able to log in to the Members Area for access to:

- **Searchable Doctor Listings** — If you are looking for a DES-aware doctor in your area, you can go to the members-only searchable Doctors List and search by city, state or ZIP code. You'll find doctors' names, practice names, specialties and contact information. These listings have been created by recommendations from DES Action members.
- **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.

- **Attorney List** — If you're interested in getting involved in possible future DES-related litigation, we offer a list of knowledgeable attorneys DES Action members have shared with us who might be able to help.
 - **Exclusive Content** — an expanding collection of articles and videos accessible only to current DES members.
- And more!** Update your mailing address, pay your membership dues or make a donation online.

DES Action USA on Facebook

Like DES Action USA on Facebook and follow us on Twitter to stay up to date on medical and environmental health news that affects you, your loved ones and the planet. Share your thoughts with an engaged and active community. There's a ton of information swirling online 24/7 that affects the

DES population — don't let it pass you by!

Online Support Group for DES Daughters

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.

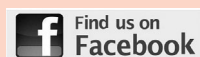
What we talk about is private — just between us — so we can feel free to raise questions on topics we aren't comfortable bringing up with others. What is amazing is the depth of knowledge in the responses.

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: DESActionDaughters-subscribe@yahoogroups.com.

New Website Information

We're changing to a new membership program to improve our service. The big thing to know is that we've reset the passwords. The new default password is: **desUSA?&B5V**

You'll find the same great content: a searchable list of doctors, a list of lawyers, and back issues of the VOICE in flipbook and PDF formats.



MISSION STATEMENT

The mission of DES Action USA is to identify, educate, empower and advocate for DES-exposed individuals.

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Endocrine-Disrupting Chemicals

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male/female body functions. The hormone oxytocin plays a role in social relationships. Leptin, a hormone made by fat cells, tells the brain when the body has had enough to eat, decreasing a person's appetite. Ghrelin, its counterpart, stimulates hunger.

As one of the most potent man-made hormones, DES had such devastating effects because it interrupted the normal functioning of this system, like a rogue construction crew throwing up roadblocks that stopped the body from receiving essential instructions needed during development.

Chemicals that have this derailing effect are called endocrine disruptors. The effect could be minor—an extra speed bump—or major, such as switching train tracks or removing part of a road. And evidence is building that endocrine-disrupting chemicals absorbed by the body may lead the body to gain more weight, as a recent research paper described in the research journal *Current Obesity Reports*.

Researcher Philippa Darbre, from the University of Reading in England, explained the evidence so far on these endocrine-disrupting chemicals, called “obesogens” because of their ability to cause weight gain. Scientists still have a lot to learn about how these chemicals operate and may affect the body, but our environment is already largely saturated with these endocrine disruptors. The questions are how much our bodies absorb them and how much of an effect they might have—both questions without clear answers at the moment.

“Some of these compounds are present in nature, such as plant phytoestrogens, but the majority are synthetic chemicals which have been released by human activities

into the environment without any prior knowledge of their effects on ecosystems or human health,” Darbre wrote in the paper. Aside from DES, below are the main categories of endocrine disruptors.

Classes of Endocrine Disruptors

TBT - Tributyltin was used for years in the paints for ship hulls because it prevented barnacles, snails and other creatures from growing on the hull and increasing the weight of a ship. It's now on the way to a complete global ban because it causes female clams and fish to grow masculine features. We don't know much about how it affects human health.

POPs/DDT/PCBs - Persistent organic pollutants are a broad class of chemicals that include the insecticide DDT and polychlorinated biphenyls (PCBs) used in industrial manufacturing. Many of these compounds are stored in fatty tissues and can interrupt endocrine functioning.

BPA - Bisphenol A and phthalates are both used in manufacturing plastics. Research suggests that BPS, often used to replace BPA, acts similarly to BPA. (See our interview with Professor Robert Martin in this issue.) These compounds are among the most common man-made chemicals: They exist in water bottles, canned foods, toys, packaging, electronics, flooring, air fresheners, personal care products, clothing, pharmaceuticals and medical equipment. Their effects on humans seem to be mild, but scientists are still learning about them.

PBDEs - Polybrominated biphenyl ethers are flame retardants that can interfere with the human thyroid. Most PBDEs are now banned, but they persist in the environment and are found in nearly all people's tissues. Prenatal exposure to PBDEs has been

linked to negative effects such as decreased IQ and attention.

Parabens are preservatives used in many personal care products, foods, pharmaceuticals and paper products to kill bacteria.

Phytoestrogens occur naturally in soybeans, legumes, lentils and chickpeas.

How They Might Affect Human Health

While all of these chemicals have the potential to interfere with the human endocrine system, it's not clear how much they do, and it depends on a person's total exposure. Humans are most susceptible to these compounds' effects during fetal development and in the first few months after birth. Interestingly, they have a sort of Goldilocks effect: Exposure to a very small or large amount has a greater effect than an exposure somewhere between those extremes.

Most research into these compounds comes from mouse studies, in which mice exposed to these chemicals gain more weight than unexposed mice. Transgenerational effects have been seen in mice as well, where a mouse prenatally exposed to these chemicals passes on characteristics caused by the exposure to their offspring even if their offspring was not exposed.

However, mice still differ from humans, and it's not clear how big the effects of these chemicals might be on humans. Darbre noted that the increase in obesity among children under age two suggests some kind of interference with development is occurring early in life. It's unlikely such young children are eating enough extra food and getting so much less exercise than past generations to explain the weight increase.

Darbre explained several ways endocrine disruptors could

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Q&A with a Member: Deborah Shaffer



Deborah Shaffer

It was only when Deb Shaffer decided to have a baby in her 20s that she learned her mother had taken DES during pregnancy. She told her mother that she and her partner of six years planned to try conceiving. Shaffer's mother told her about taking DES while pregnant, setting Shaffer on a journey to learn what it meant to be a DES Daughter. Shaffer's story inspired fellow filmmaker Stephanie Poleski to film the documentary DES: Time Bomb Drug in 1983, aided by Shaffer as associate producer. Shaffer was also one of 12 women represented by attorney Sybil Shainwald who won settlements from smaller DES manufacturers that didn't initially settle as Lilly, Bristol-Myers, Squibb and larger companies did.

Q: How has your DES exposure affected your life?

A: Until my mid or late 20s, there was no visible sign that there was anything to worry about. And then, through my late 20s and 30s, I had a series of all the problems that DES Daughters commonly have. I have no idea how many times I was diagnosed with dysplasia (the development of abnormal cells in the narrow neck of the cervix). Then I'd have procedure after procedure after procedure—a little cryosurgery, a cone biopsy, painful colposcopies every six months—and I was plagued with a lot of infections and minor problems.

I don't know if all those were related to DES or not, but I definitely entered quite a long period of DES problems to the extent that, in the long run, I couldn't hold a pregnancy. I have a T-shaped uterus and a hooded cervix, and I had two miscarriages. I'm sure, in retrospect, that I was pregnant more than twice, but fertilized embryos wouldn't implant in my uterus. It was a hostile environment for an embryo. You know how they say you can't be a little bit pregnant? I was. [When Shaffer was nearly 40, she accepted that she would not carry a pregnancy to term and adopted a daughter, now age 28.] I remember saying to people at the

time that my problem got solved. I'd been living with such a struggle for so long, but I felt very lucky that in my case, I never had cancer.

Q: Tell us about the legal case you were involved in.

A: I had many companies that had settled with me, and then some very small companies said, "We're not going to settle." Sybil replied, "We're going to take you to court. You're not going to get away with this." There were several women who had severely premature births and severely compromised children.

With those 12 cases, everybody won, and it was a really big moral victory because we got a huge settlement from the judge and jury. In the end, we didn't get paid anywhere near as much as was published in the paper [the amount the small companies paid was a percentage based on their market share], but that didn't matter because that wasn't the point.

Q: How does being a DES Daughter affect your life today?

A: I'm very, very vigilant. Because of the DES, I feel I owe it to myself to be extremely vigilant about my own health, so I'm a very good patient. I've always followed all the recommendations for my age and always gotten my mammograms,

colonoscopies and screenings.

I did do some things that weren't recommended for DES Daughters. When I entered menopause very young, at age 40, I had mood swings, hot flashes and other symptoms, so I did take hormone therapy up until the big study came out that recommended not taking it. In retrospect, would I do that again? Probably not. Right when I quit the HRT, I was diagnosed with lobular carcinoma in situ (LCIS) in my breast, and that was extremely traumatic to go through.

Today, I don't feel I'm in drastically different shape than other women my age. The eras of active problems in my 20s and 30s were much more fraught. I spent years going through horrible procedures, and I'm grateful I don't seem to have to go through that anymore.

Q: How has DES Action been helpful to you?

A: I've probably been a member since the beginning. I've never been active in the listserv, but I read all the newsletters cover to cover. I want to keep up with any new findings, so it's helpful in that way. It's also very helpful knowing there's a community of people who understand.

Q: In what ways has being a DES Daughter influenced your

perspectives on the medical and pharmaceutical industries and on government regulation?

A: It has affected my view of the pharmaceutical industry for sure. I have no love lost for the pharmaceutical companies, and I'm very skeptical always about any claims that have to do with any pharmaceutical products. But I think modern medicine is miraculous. The problem is that medical research is at the service of making money, and not for people's health.

I'm not convinced that all areas of our food, such as food additives and hormones in animal feeds, are being properly regulated across the board. I'd like to see better attention paid to the bigger picture of health in modern Western society and how we deal with medicines. I'm very interested in how we create sustainable living ecosystems that can go on far into the future, and the story of DES is one piece of that. We've got to get the profit motive out and get planetary health and individual health to be the priorities. **DES VOICE**

CORRECTION

An article on cervical cancer screenings in the previous issue suggested that clear cell adenocarcinoma—the cancer DES Daughters are at highest risk for—is not as substantial a concern now that DES Daughters are older because their increased risk had been seen in adolescence and young adulthood. However, CCA, though still very rare, occurs primarily in postmenopausal women, and several DES Daughters in their 60s and 70s have been diagnosed with it. DES researcher Rebecca Troisi says, “We are still concerned that new DES-related cases of CCA could develop as the women enter the age in which it is more common (although still quite rare). We have not observed any new cases past age 39 so far, which is somewhat reassuring.”

Karen Calechman Named DES Action Community Manager



Karen Calechman

DES Action USA is proud to welcome a new member to our team: Karen Calechman, a DES Daughter ('56), is the new DES Action Community Manager. After initiating and helping implement the two DES Action Symposia, “DES: A Population Health Tragedy,” it became evident that Karen's experience in education, outreach and event planning would be a substantial asset to our work.

This is an expansion of Karen's responsibilities. For the past six months Karen has been fielding phone calls on the DES Action 800 telephone line. By handling the phones, Karen has already begun helping DES-exposed individuals understand how their exposure might have affected them and their children, and how complicated it is for researchers to confirm what conditions DES exposure can cause.

“Probably the hardest challenge is to listen to very ill people on the phone who just want definitive answers and help,” Karen said. “We always ask if they have a support system of family, friends, therapists and

doctors who are there for them.”

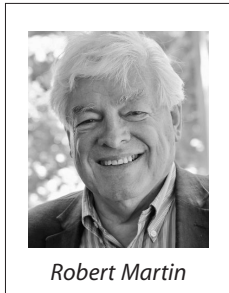
Karen's primary duties include managing daily responsibilities of the membership community, such as answering phone calls and emails from members, implementing educational initiatives, working with the listserv members and contributing to website updates. In a broader sense, Karen's role extends to becoming as knowledgeable as possible about DES history and side effects and to keep abreast of new and ongoing research as she establishes mutually beneficial relationships with other organizations.

“In short, my job is to meet our members' needs and to recognize new opportunities,” Karen said. She also hopes to develop several new projects, such as a guiding document for therapists to help them understand the emotions and struggles of DES-exposed individuals.

“I would also like to do more education initiatives to bring awareness to the medical community and public that DES exposure is not a dead issue and is now affecting the third generation,” Karen said.

If you have questions about DES history or research; membership; if you need a doctor list for your region; or if you have new ideas you'd love to see DES Action tackle, contact Karen Calechman at karen@desaction.org. **DES VOICE**

Field Museum Researcher Robert Martin on DES



This past summer, Professor Robert Martin gave a lecture at The Field Museum in Chicago called “The History of Accidental Estrogens in Our Environment,” including the history of DES. Martin is a biological anthropologist and Emeritus Curator of The Field Museum’s Integrative Research Center. He is author of How We Do It: The Evolution and Future of Human Reproduction (info: goo.gl/Jtrrwu). Here, Martin shares what he has learned in his research and the message he passionately wants to convey about endocrine-disrupting chemicals (EDCs) in our environment.

Q: What led you to begin researching endocrine disruptors such as DES?

A: I learned about endocrine disruptors as I was writing my book *How We Do It*. I kept stumbling over things that mentioned EDCs, and I realized we have a major problem with environmental pollution from chemicals acting like steroids in our bodies.

When I heard about Nancy Langston’s book, *Toxic Bodies: Hormone Disruptors and the Legacy of DES*, I at once read it cover to cover and made extensive notes. One question I had is, why are we having the same problems 40 years later after learning about the problems from DDT and DES? Why are we letting all these other substances through, such as BPA, when we have similar evidence about them? It shouldn’t be happening.

Q: What did you learn about the early history of DES in your research?

A: A lot of what we know about EDCs goes back to a scientist named Sir E. Charles Dodds who was studying artificial organic chemicals in London in the 1930s. Dodds’ aim was to find a cheap estrogen, and he found a family of about a dozen compounds that all have estrogen-like effects to varying degrees. These included BPA and BPS, but they turned

out to be less potent than DES. When his lab synthesized DES, he completely lost interest in BPA. But he showed back then that BPA and these other chemicals had an estrogen-like effect on the uterus and ovaries.

The interesting thing with DES was that it was originally given for estrogen replacement therapy as a fake estrogen, and that probably didn’t cause too much of a problem because the major effects are not on an adult, but on a fetus. [DES exposure in mothers, however, did increase risk of breast cancer.] Physicians began to use it more generally, especially during pregnancy, in the unfounded belief that it reduced the risk of miscarriage. The industry was using advertisements that said, “Take DES to make normal pregnancy more normal.” That doesn’t make any sense.

Now we know that really small doses of DES can have really big effects, and this carries over several generations — up to six generations in rats and mice. So this could be with us for decades, and unfortunately there’s nothing we can do about that except treat the symptoms.

Q: What can or should be done about other EDCs?

A: Many products say they are BPA-free, but they have BPS, from the same family of chemicals.

I think it’s absolutely cynical to replace BPA with another member of that family. It could be that some of the other members of that family have a weaker effect, and it’s possible some have a stronger effect, but they all have some kind of estrogenic effect.

I think we should ban this whole class of chemicals. I met a recently graduated chemist whose first job was working at a firm that made plastic toys for a fast-food chain. His job was finding a replacement for BPA. He said, “They told me to look at other chemicals in that family that were not on anybody’s radar screen.” He was told to find a different chemical — not because it was safer, but because it wasn’t banned and no one knew about it.

The problem in the industry is that they will get away with it as long as they can. There are a lot of business people out there who want to avoid any kind of control as much as possible, regardless of whether such chemicals might cause cancer. The only thing that stands between us and these chemicals is the EPA. People need to know that the EPA was founded as a direct result of the DDT story and Rachel Carson’s book *Silent Spring*. The EPA is there to protect us against poisons in the environment, and I hope as many people as possible stand up and say enough is enough.

Endocrine-Disrupting Chemicals

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contribute to weight gain:

- Increasing fat cell numbers
- Increasing the size of fat cells
- Changing how the endocrine system manages fatty tissue development
- Interfering with hormones that influence appetite
- Altering a person's metabolic rate—how fast they burn calories
- Causing the body to store calories instead of using them
- Altering how the body processes insulin and fats in endocrine tissues
- Increasing the body's likelihood

to store endocrine-disrupting chemicals in general, possibly compounding their effects.

Some scientists believe these chemicals partly explain why obesity is linked to chronic diseases such as diabetes, cancer and heart disease. The body's exposure to these endocrine disruptors might contribute to both obesity and those other diseases, though we need more evidence.

The silver lining is that none of these chemicals has been shown so far to have effects as disastrous as DES, and some effects may be small enough that they do not harm a person's health. It's also good

news that several of them have been banned, and some companies throughout the world are choosing to voluntarily stop using them. But other chemicals continue to be used in manufacturing.

It's not possible to completely eliminate exposure to them since all these chemicals, including DES, remain in our environment—even years after being banned from use. But people can reduce their exposure by choosing as many products as possible that don't contain compounds such as phthalates, BPA or BPS, PCBs and parabens. They can also advocate for stronger federal regulation of endocrine disruptors. **DES VOICE**

Stupid Cancer

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of participants they can choose to contact.

After learning about DES Action and the multiple cancers that DES is linked to, Fuehrer included "DES-exposed" as a category. "Even though the condition is different, the isolation and the fear is exactly the same," Fuehrer said.

To support DES Action, the app includes an area for our DES community. After you download the free app, you will be asked "What was your primary diagnosis?" Select the "DES-exposed" option in the list and you'll be instantly matched to others. You can read their profiles on the Discover tab and communicate with others who understand what you're going through because they're going through it too.

The app does differ from other social networks in two critical ways: The developers don't sell participants' data, and it allows truly confidential messaging between participants.

"We have followed the highest standards in privacy," Fuehrer said. He encourages all participants to

review the privacy policy and terms of use. "We also can't see what you chat about," he said. "The way the app was developed, your private chats are live on your device, and only you can see them."

do anything without asking them," Fuehrer said. "What we do is make information available on their terms."

Pharma companies are federally required to spend money learning about patients, Fuehrer said. The

The Stupid Cancer app connects you to a network of DES peers who understand what you're going through.

The app's funding structure also differs from ad-funded social networks. The app's precursor, Instapeer, launched in April 2015 but became so popular so quickly that it crashed the app. Instapeer was developed using pharmaceutical sponsorship funding.

But Fuehrer and three other cancer survivors developed the new Stupid Cancer app alone, using Fuehrer's life savings and no industry funding. Continued funding comes from partnerships with hospitals, pharmaceutical companies and other groups that pay to provide information about clinical trials or other research that cancer patients can choose to participate in if they want.

"We never sell anybody's data or

app lets them share information about those projects with the Stupid Cancer community. Initially, Stupid Cancer will email participants. Later, participants will be able to control the opportunities they see and track on a dashboard in the app.

"To me, working with Pharma isn't a bad thing if they're really trying to understand our community," Fuehrer said. "We will never take sponsorship, but we will work in those projects."

Ultimately, the app's purpose is to help participants "find someone who can relate and let you get all of the things that you thought you had to keep inside your head out," Fuehrer said. "We wanted each person's experience to be entirely subjective to what's important to them." **DES VOICE**

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Stupid Cancer App Connects DES Community Online

Are you looking to connect with others in the DES community? A new smartphone app gives those in the DES community an opportunity to seek support or provide mentorship to others with DES exposure, with a cancer diagnosis in the past or present, or with a loved one who has cancer.

The nonprofit organization behind the app is Stupid Cancer, which launched the app as part of its 10th anniversary celebration in September. Stupid Cancer is the largest cancer organization for adolescents and young adults living with cancer. But the Stupid Cancer app is designed for anyone of any age who has any connection to cancer, including DES exposure. The Stupid Cancer app connects you to a network of peers who understand what you're going through.

"The problem we really wanted

to solve is, if you call a helpline, you're completely at the mercy of the person they connect you to," said David Fuehrer, a testicular cancer survivor and the Stupid Cancer app's developer. "The purpose of the app is to put that power in your hands. If you want to talk to a mentor one moment and then someone your own age going through the same thing at the same time, you can. You choose who you're connected with instantly."

The app works similarly to other online social networks: Participants create a profile and then can join a chat room or message other participants. Profiles ask for a participant's name, birthdate, whether they have cancer or care about someone who does and the cancer type and stage (if any). Then the app shows them profiles

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