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'our Voice — DES Does Not Define Who I Am	∠
Remembering a Special DES Researcher	6
Pap Screening Info—Clip and Take	-

A Focus On Diethylstilbestrol

SPRING 2012 #132

DES and BPA: The Same Yet Different

Pay Attention to the Dose

By Fran Howell

Howls of protest erupted in March when the Food and Drug Administration (FDA) opted to continue studying bisphenl A (BPA), rather than ban its use in products that put it in contact with food. Consumer activists have been pushing for tighter regulation amid growing concerns about BPA's potential health impacts.

Like DES, BPA is an endocrine disruptor, so it falls into the category of a chemical that interferes with the way our bodies process hormones. **BPA and DES are both synthetic estrogens developed in the 1930s and have very similar chemical structures.**

DES was prescribed to pregnant women, while BPA was put on the shelf until the 1950s when its ability to harden plastics was recognized. It is so widely used that avoiding BPA has become problematic. It can be found in canned food linings, water bottles, CDs, plastic dental sealants used in fillings, and all sorts of hard plastic items such as the coffee makers in our homes.

The list of health issues that appears to be associated with BPA exposure sounds significantly similar to those known to be linked to DES exposure: reproductive tract abnormalities, infertility and breast cancer.

In the 1990s, University of Missouri researcher Fred vom Saal was examining the results of extra estrogen

exposures on embryonic development. He used DES as a control, because its impacts have been well studied. To his surprise, when he gave pregnant mice BPA, it caused enlarged prostates in male offspring, just as DES did in his studies. That sparked vom Saal's interest because BPA is in so much that is plastic in our environment.

But we don't eat plastic, so how does it get into our bodies? The answer came accidentally in the lab of researcher Pat Hunt. She was conducting an experiment that suddenly went haywire with extremely odd results from one week to the next. She eventually figured out that a lab worker had used the wrong, and stronger soap, for washing the mouse cages and water bottles. This caused the plastic to deteriorate and allowed bisphenol A to leach into the animal's food and water supplies. That is why there is a push to remove BPA from coming in contact with the products we eat and drink.

BPA, like DES, seems to affect hormonally-influenced areas of our bodies such as breasts, prostate and other reproductive organs. Studies show it has its most powerful impact on developing fetuses, babies and young children by apparently acting like an extra estrogen exposure in the body.

But this is where it gets interesting.

While the effects of BPA have been found to occur in infinitesimally LOW doses, DES was

continued on page 3

There's Still Time to Participate in the DES Action Health History Survey!

Most of us don't have the opportunity to participate in DES health studies like those at the National Cancer Institute or the National Institute of Environmental Health Sciences. But we have health experiences that may provide clues and additional information to these researchers, which is why we embarked on this DES health survey.

And, for the first time, DES Action USA has invited the international DES-exposed community to participate, too.

Epidemiologist Deborah Wingard, Ph.D., Professor in the Department of Family & Preventive Medicine at the University of California San Diego, is leading this survey effort for DES Action.

The deadline for filling out and returning a Health History Questionnaire is June 15, 2012. Please visit DES Action website at www.desaction.org to complete the online survey, or contact us for a hard-copy version (info@desaction.org or 800-337-9288).

VOICE Schedule for 2012

If you noticed this issue of the VOICE comes closely on the heels of the previous one, you are correct. The winter issue was delayed because it took longer than expected to finalize details for our DES Health History Survey, which was included in it.

This issue is right on schedule and all future issues of the VOICE should be as well. We are back on track and apologize for any concern the late mailing may have caused.



DES Action USA

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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 Online 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
Online Support Group simply send a blank e-mail to:

<u>DESactionDaughters-</u> 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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The DES Link to Uterine Fibroids

"Early-Life Exposures and Early-Onset Uterine Leiomyomata in Black Women in the Sister Study," Aimee A. D'Aloisio, et al, *Environmental Health Perspectives*, Vol. 120, No. 3, March 2012.

Reviewed by Kari Christianson

Once again, DES topped the list of early-life exposures that were associated with early-onset uterine fibroids. This research article, now that enrollment for the National Institute of Health's Sister Study has been completed, analyzed baseline health information from 3,534 black women, 35–59 years old, about early-life exposures, just as a 2010 article reported on early-life factors found in non-Hispanic white women. Early-onset fibroids in this study were diagnosed by the age of 30 years old.

The researchers report, "In utero DES was one of the early-life exposures that was most strongly associated with early-onset fibroids among black women.... In addition, our finding for black women was similar to that for white women in the Sister Study."

Other factors, besides DES exposure, associated with early-onset fibroids were maternal pregnancy or gestational diabetes and monozygotic (developed from one egg) multiple birth. Additional associations identified in this study were being taller or thinner at age 10 and other early-life factors, such as being the firstborn child of a teenage mother, maternal hypertensive disorder, preterm birth, and having been fed soy formula.

The Sister Study is a long-term research project, following 50,000 sisters of women who have had breast cancer. While investigating breast cancer is the goal of this project, a detailed health history about all early-life exposures has been gathered from participants. Analysis of these and other factors, along with current health outcomes, provides invaluable information about the health effects of many environmental and early-life exposures.

Researchers at the National Institute of Environmental Health Sciences (NIEHS) previously reported on the incidence of uterine leiomyomata (fibroids) in non-Hispanic white women (*see VOICE #124*). Both the 2010 and 2012 research articles suggest an elevated risk of early-onset uterine fibroids among women who were prenatally exposed to DES.

Still, the authors acknowledge that the women who reported prenatal DES exposure "may have received more gynecologic screenings, which could have lead to a greater likelihood of detecting early-onset fibroids. Further studies of DES are needed in different study populations to support involvement of fibroid pathogenesis."

Once again, the call for additional studies about the role of prenatal DES exposure and other hormonally active substances to the development of uterine fibroids—and other adverse health effects—is clear from this group of researchers.

DES and BPA from page 1

prescribed to pregnant women in HIGH doses! It is an important distinction to keep in mind and scientists are trying to unravel what is going on. Why do many of the same health effects show up in prenatal low dose BPA exposures as in prenatal high dose DES exposures?

Meanwhile, as the FDA dithers about regulating BPA, consumers are left on their own for protecting their health. Luckily, it's becoming easier because companies like Campbell's Soup are planning to remove BPA from their packaging and other firms now sell BPA-free plastics. Also, several states and communities have banned the sale of BPA food containers or products for children. Of course, no one yet knows how safe the BPA replacement chemicals will be!

Breast Cancer Lawsuit Update

The latest regarding the DES breast cancer litigation in Boston is not what we wanted to hear from the drug companies. Mediation talks on April 3-4, 2012 were unsuccessful between the DES Daughter plaintiffs and drug makers.

As a result, Federal Judge Marianne Bowler has scheduled January 7, 2013 as the date when this product liability case goes to trial. Attorney Aaron Levine from Washington, D.C., is representing the women.

The Fecho sisters, a family of four DES Daughters from Pennsylvania, will be the first of the 53 cases to be tried in court. The four suffered infertility along with DES-linked reproductive tract abnormalities. They then contracted breast cancer with each diagnosed between the ages of forty and fifty. Of note is that a fifth Fecho sister is not a party to the lawsuit. She wasn't exposed to DES, was able to have a child and remains cancer-free.

DES Action USA is following this litigation and will provide updates in the VOICE and on our website: http://www.desaction.org as well as via the DES Action Facebook page.

YOUR VOICE

This article, by DES Action USA member Joanna Katzen, is another in a series of personal stories to be published in the VOICE. We hope you enjoy reading about the spirit of our members who are living good lives in spite of, and with, DES exposure. Do you have a DES story that communicates hope? Please email us at info@desaction.org for more information about submitting it.



I'll never forget how devastated my mother was, knowing she had inadvertently done something that harmed me. It was a time when we rarely saw emotion expressed publicly by our parents. An adult crying just wasn't acceptable, and I don't think I ever saw my parents, or my aunts or uncles, cry. But the first time my mother took me to the doctor for a DES-related exam, she was on the verge of tears. Subsequent conversations about my DES exposure were puzzling. It was hard for me to understand what was being said, while witnessing the emotion my mother tried so hard to hold back but could not.

What had happened? Well, as we all know, doctors were (are?) viewed as gods, and a certain god had offered my mother a solution to her problems in the form of a pill. And it seemed to work at the time. Never mind the ramifications, we all want to solve our problems in the easiest way possible. I'm currently struggling with learning to play the guitar. I really wish someone could give me 'guitar-in-a-pill expertise!' Oh, yes, I want it so bad, but would I take it if offered?

Today we know to ask questions of our doctors, but do we know which

ones to ask or how to decipher the answers when they come? Do we trust them? And in times of extreme need or stress, do we really want to know?

Right now, I'm dealing with lots of questions regarding what looks like the onset of chemotherapy-induced osteoporosis, and basically, there aren't a lot of answers. Did doctors know about this possible outcome when they offered me my potential cure? Did I know to ask the correct questions? Did I care? I was faced not with an unrequited longing to have a baby, but with looming death at a time when I had just been divorced and had two teenagers to raise on my own.

I think making medical decisions during a time of great stress is one of the most difficult things anyone can do. It's human nature to want help with these decisions and in our uncertainty we often rely on doctors to make our decisions for us. What can we do to enable an improved decision-making process during our times of upheaval and need?

Happily, I'm now in a position where I can calmly ask myself that question. I am a DES Daughter and a sixteen-year survivor of breast cancer. My children are safely grown, and I am finishing my second year of studying music at the Berklee School of Music in Boston, having relocated here after twenty-three years in Israel.

For now, the only answers I can come up with include finding Primary Care Physicians we can trust, so we can ask all of our questions without losing the doctor's attention. I believe that community and open communication is key as well. For us DES Daughters, and perhaps for our children, keeping current with research and legal processes being either taken, or considered on our behalf, is crucial. Since none of us can

do this on our own, staying connected with the DES community via the DES Action DES Daughter listserv and Facebook have been invaluable for me.

But mostly, we should do our best to avoid all of the mistakes that we can. We should remember that yes, expressing our emotions is normal, even to our children, and publicly as well. When we are faced with urgencies, such as a crucial medical decision, we ought to talk with as many people as possible. Then, make as informed a choice as possible, knowing we will, ultimately, have to live with all of the ramifications. Enlist the help of your family and friends without shame or embarrassment. I believe that when we do this, not only do we get the help we need, but also we show others that they can do the same.

I think my mother lived with the words, "if I had only..." looming over her head. I never blamed her for my DESness, though I know she blamed herself. I wish she would have let it go because back then, no matter who was asked, the answer probably would have been to do what the doctor prescribed. Times are different now and valuable information is significantly more readily available and should be accessed.

Yes, DES is an integral part of who I am, but it does not define me. Neither does my breast cancer. Both of them, and many other obstacles I've faced, are nothing more than walls against which I refuse to butt my head.

Instead, I do my best to find my way around walls. It is how I choose to continue on in this wonderful existence filled with as much adventure as possible. We each have choices in life to make, so gather what you need to know, choose wisely, don't look back in regret and enjoy the ride!

In Honor of Our Unsung DES Heroes!

There is no one particular way in which families handle DES exposure. Unfortunately, it tore some apart but others grew stronger together. Much is made of the interactions between DES Mothers and Daughters, but we haven't spent time recently acknowledging ways in which the DES experience affects the men in our lives. With Father's Day approaching we thought this would be a good time. Many thanks to members from our DES Daughter Online Support Group Listserv (see pg 2) for sharing thoughts about the Unsung DES Heroes in their lives.

My Man Drew has been my medical security blanket for over 40 years of DES-related medical challenges. He has been at my side for several miscarriages, biopsies, and all my other DES surgeries. His dedication has been truly phenomenal, e.g., when we finally had our daughter, Katie, he sat with her in the neonatal ICU day after day because I couldn't be with her—he felt that she needed to be held and talked to whenever she was awake—that's my unsung hero!

— Jane

My father was a World War II veteran who served with the Royal Canadian Navy and was actively involved in fighting on the Atlantic Ocean. The War changed my father. He became a quiet man and kept his thoughts to himself. Children were extremely important to the veterans and like most returning from the War, having a family was extremely important to him. My sister was stillborn and my brother was born alive but lived for only 15 minutes. When my mother discovered she was pregnant again, she was given the wonder drug, DES. Approximately three weeks before I was born, she was hospitalized and placed on 24-hour bed rest. My father quietly offered his love and support to Mom and his unborn child, praying I would

be born alive. That was his way. Later he quietly offered his love and support to me when I found out about my DES exposure. He accepted that I was unable to have children, meaning he would have no grandchildren. But my father let me know he was grateful that I was born.

— Pat

When Time Magazine published its DES article in 1971, my dad immediately recognized diethylstilbestrol as the drug prescribed to my mom. How he remembered two decades later amazes me still! Dad's life ethic is my role model. Work hard, with a slice of humor thrown in, respect others and take the high road. Dad was mom's rock during her victory over breast cancer, and he followed the pain of my infertility, sharing deep joy when, via adoption, he welcomed his fourth granddaughter. Perhaps the lesson from dad I treasure most is to avoid looking back in regret. Instead, enjoy what I have now while facing forward to the future. I am lucky because I can still thank him - so when you read this, dad, consider yourself hugged!

— Fran

At 36 I answered a personal ad which said he wanted "a real relationship and to get married and have kids." Two years later Jock and I married when I was 38. Due to our age we started trying for children as soon as we got engaged. After four years of infertility I was finally diagnosed as a DES Daughter and told I would never carry a child. I worried Jock would leave. I told him I wouldn't blame him—I was a "lemon." He looked at me and said, "I just know we're going to have a child; we will do it." He never wavered and was there for every single test and held me through lots of tears. And he got really, really good at giving me the fertility injections. Jock was

right. Thanks to a surrogate our baby is now six and the light of our lives. Jock Tardy—you are my hero!

— Linda

Before the public discovery of what DES had done to millions of families, including my own, I knew I was a member of a very special closeknit family. We freely talked, aired concerns and showed our love for one another. As early as I can remember, my Dad taught us kids to be inquisitive, enjoy each day and do everything possible to protect ourselves from harm. Dad was concerned for my sister and me when medical tests showed DES harmed us both. My years of infertility continued as my wonderful husband and I tried in vain to have children. Miscarriage, surgeries, biannual tests were common and hurt us all. Dad phoned one day with the name of an attorney who had just won a case representing a DES Daughter. His voice trembled as he told me to call this lawyer right away and encouraged me to SUE those 'drug makers' (not his words) for leaving us all childless. Several times since, my Dad told me he is sorry that 'this' happened to me. He wanted so much to be a grandfather to the children we should have had. Of note, my sister delivered a boy 8 weeks premature, following miscarriages. Though stricken with severe cerebral palsy he is our 'miracle' baby and my precious nephew. I'm so glad Dad has his Grandson.

— Linda

Poor Dads. What do they say? My Dad was no exception. One day he just came over and asked, "You okay?" My reply was, "I'm okay; you okay?" So our tradition began. Until his passing several years ago, we never hung up the phone without saying those special words.

— Sharon

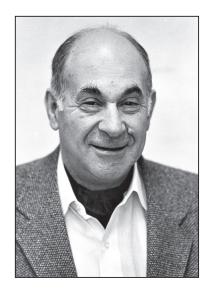
PEVOICE

Remembering One of the First DES Researchers

Howard Bern, known as a founding father in the field of endocrinology and a pioneer in studying how hormones affect fetal development, passed away peacefully at the age of 91 after a long battle with cancer.

Bern, professor emeritus of integrative biology at the University of California, Berkeley, was one of the first scientists to focus on the harm caused by DES. "He was instrumental in recognizing that many synthetic chemicals can act as 'endocrine disruptors," says developmental endocrinologist Tyrone Hayes, a UC Berkeley professor who adds, "Bern's groundbreaking work on DES was critical in the development of studies in this area."

Alan Bern remembers his father as



committed to encouraging and developing students both in science and in their passions. While supporting them academically, he also supported "...students arrested for their political activity in the Free Speech Movement."

Echoing the sentiments of most researchers who came to know Bern, DES researcher John McLachlan of Tulane University says, "Howard helped me understand the obligation of scientists to speak out regarding their work and what it meant to the common good. He and Arthur Herbst championed the cause of DES and marshaled the scientific information needed to make decisions about its use. He never shied away from a good fight and he taught me to be pugnacious about the right course of science in the public good. I feel a great loss in the fabric of scientific integrity and humanitarian fierceness with the loss of Howard." **DESVOICE**

LETTERS TO THE EDITOR

Our mailbox overflowed in response to VOICE issue 130. Most of the comments were about our DES poetry collection, and we even received another submission.

I found the poems in this issue very moving and, though I myself have never written any poetry on the subject, a few pieces reflected my experiences as if by my own hand!

— Pam

I got my copy of the VOICE with all the poems. Thank you for including mine! This is a great collection of poetry from excellent writers. I'm really honored to have my poem included with theirs. I rarely mention the newsletter to my mom, because she still feels awful

about what happened as a result of DES. But today I showed her the VOICE and pointed out the poetry. She looked at the poems and said she was proud of me, so I am glad that outweighed any residual guilt.

— Paula

Thanks for your last issue of the VOICE. I read and reread the poems. I am a DES Mother – the poems really hit home.

— Irene

The poems are incredibly touching. Who knew people were so anxious to "get this off their chest" in such a way? Truly lovely!

— Chris

MY JOURNEY

By Laura Sauer

I am a DES Daughter I'm DES exposed A genetically altered Lady Author of this repose

I was told during my childhood Of my possible DES fate Of clear cell adenocarcinoma Much more added as of late

Snow White and her seven specialists That's who I've recently become As I continue my estrogen-laced journey I will live my life with aplomb.

PES VOICE

New Pap Guidelines Do Not Apply to DES Daughters

Without a doubt your health care provider is aware of the cervical cancer screening guidelines released in March 2012 by the U.S. Preventive Services Task Force (USPSTF). The recommendations advise against yearly Pap exams saying most women can skip years.

But your provider may not be aware of an important disclaimer that affects DES Daughters. It's right there in the third paragraph under Recommendations where it clearly states that, "This recommendation statement does not apply to women with in utero

exposure to diethylstilbestrol."

You can tell your doctor, or better yet, clip out the guidelines to bring in when you go for your next Pap exam. It helps to have backup confirmation from a respected resource, in this case the USPSTF, when advocating for the care you need.

A proper DES Daughter Pap exam involves scrapings of cervical and vaginal cells because of the increased risk for clear cell adenocarcinoma (CCA) of both the vagina and cervix.

This also holds true for DES Daughters who have had a hyster-

ectomy. They require a yearly Pap screening because the vagina remains and therefore is at risk for CCA, even though the cervix was removed in surgery.

Unfortunately, many doctors are under the misconception that after age 30 DES Daughters no longer should be concerned about an increased CCA risk. However, DES Daughters in their 40s and 50s have been diagnosed with this cancer. Even though the numbers are small, they do exist. At this time there is no known upper age limit for the development of CCA.



Screening for Cervical Cancer: U.S. Preventive Services Task Force Recommendation Statement

Virginia A. Moyer, MD, MPH, on behalf of the U.S. Preventive Services Task Force

Abstract

Description:

Update of the 2003 U.S. Preventive Services Task Force (USPSTF)recommendation statement on screening for cervical cancer.

Methods:

The USPSTF reviewed new evidence on the comparative test performance of liquid-based cytology and the benefits and harms of human papillomavirus (HPV) testing as a stand-alone test or in combination with cytology. In addition to the systematic evidence review, the USPSTF commissioned a decision analysis to help clarify the age at which to begin and end screening, the optimal interval for screening, and the relative benefits and harms of different strategies for screening (such as cytology and co-testing).

Recommendations:

This recommendation statement applies to women who have a cervix, regardless of sexual history. **This recommendation statement does not apply to** women who have received a diagnosis of a high-grade precancerous cervical lesion or cervical cancer, **women with in utero exposure to diethylstilbestrol**, or women who

are immunocompromised (such as those who are HIV positive).

The USPSTF recommends screening for cervical cancer in women age 21 to 65 years with cytology (Papanicolaou smear) every 3 years or, for women age 30 to 65 years who want to lengthen the screening interval, screening with a combination of cytology and HPV testing every 5 years. See the Clinical Considerations for discussion of cytology method, HPV testing, and screening interval (A recommendation).

The USPSTF recommends against screening for cervical cancer in women younger than age 21 years (D recommendation).

The USPSTF recommends against screening for cervical cancer in women older than age 65 years who have had adequate prior screening and are not otherwise at high risk for cervical cancer. See the Clinical Considerations for discussion of adequacy of prior screening and risk factors (D recommendation).

The USPSTF recommends against screening for cervical cancer in women who have had a hysterectomy with removal of the cervix and who do not have a history of a high-grade precancerous lesion (cervical intraepithelial neoplasia grade 2 or 3) or cervical cancer (D recommendation).

The USPSTF recommends against screening for cervical cancer with HPV testing, alone or in combination with cytology, in women younger than age 30 years (D recommendation).



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Moving? Please let us know...

On Receiving Eli Lilly DES Pill Bottles

By Fran Howell

I've only seen photos of DES pill bottles, so it was with great excitement that I opened the carefully packaged box. One of our members, who wishes to remain anonymous, graciously sent us three Eli Lilly diethylstilbestrol bottles.

It was something of a shock to see them. Because DES looms so large in my life, I expected they would be bigger. But the biggest is 2 ½ inches tall, with the others measuring just two inches in height.

The little amber colored glass bottles are screw top
— not safety sealed in any way. Haven't seen a bottle like that in a very long time!

Makes me wonder whether the DES my mother was prescribed came out of bottles just like these.

Luckily for me, they were empty. I had wrestled with the decision about opening them if they contained DES

pills. I think I probably would have done so out of curiosity, but I was spared the agony of that decision. Clearly DES pills were tiny. Each small bottle held 100.

A message on the side of the bottles is explicit: "WARNING – This

s is explicit: "WARNING – This is a potent drug and serious conse-

quences may result if used other than under constant medical supervision." I guess they forgot to mention that serious consequences would result when used under constant medical supervision, too!

We have no plans at the moment for the Lilly DES pill bottles, but now we have them for historical purposes. They help us keep our focus on DES in a very real and tangible way.

