

# Reports of Potential Birth Defects in DES Grandchildren Raise Questions

## The List Is Long But Nothing On It Has Been Conclusively Linked To DES

“Birth Defects in the sons and daughters of women who were exposed in utero to diethylstilbestrol (DES),” Linda Titus-Ernstoff, et al, *International Journal of Andrology*, Early View, 30 November 2009.

### Reviewed by Kari Christianson

The most-asked questions from DES Daughters and Sons who have birth children are: Will DES affect the next generation? And how?

A new research report raises its own questions. Linda Titus-Ernstoff, Ph.D., and her colleagues with the National Cancer Institute (NCI) DES Follow-up Study analyzed responses to questions about birth defects from both DES Daughters about their children and DES Granddaughters about themselves. The DES Daughters and DES Granddaughters participants are matched with women who were not exposed to DES either as DES Daughters or DES Granddaughters.

As Titus-Ernstoff states, “a question with widespread implications for environmental contaminants is whether prenatal DES exposure in humans causes epigenetic changes that may be transmitted to subsequent generations (“Epigenetic” refers to the way genes function or express themselves. An epigenetic change affects the expression of the gene without mutating its DNA sequence. Epigenetic alterations are

thought to extend into future generations, which is why the health of DES Grandchildren is of particular interest).

Participants named many different birth defects. From the mothers of DES Grandsons, “the most frequently reported anomalies in sons were genitourinary anomalies, skeletal anomalies and heart defects.” The genitourinary anomalies “included horseshoe-shaped kidney, renal agenesis, born with one

kidney, hypospadias and testicular atrophy; skeletal anomalies included scoliosis, clubfoot, polydactyly, torticollis and hip dysplasia; heart defects included heart murmur, ventricular septal disease, tetralogy of Fallot, atrial septal defect and pulmonic stenosis.” None of these defects, however, were statistically associated with DES exposure in the mother, the DES Daughter.

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## New Guidelines For Paps Do Not Apply To DES Daughters

### Yearly Paps Important But You May Need To Tell Your Doctor

#### By Fran Howell

DES Daughters remain the exception to the rule in new cervical cancer screening guidelines established by the respected American College of Obstetricians and Gynecologists (ACOG).

While the updated recommendations call for less frequent Pap tests for most women (every two to three years instead of annually), the report specifically spells out that:

*Women with certain risk factors may need more frequent screening, including those who have HIV, are immunosuppressed, were exposed to diethylstilbestrol (DES) in utero, and have been treated for cervical intraepithelial neoplasia*

*(CIN) 2, CIN 3, or cervical cancer.*

DES Daughters should have their annual Pap/pelvic exams every year to check for clear cell adenocarcinoma of the cervix and vagina.

The new ACOG guidelines do not change recommendations for DES Daughters, which ACOG has held for years. But some doctors may be unaware of that, so you can visit the ACOG web site to read and print the updated recommendations:

[http://www.acog.org/from\\_home/publications/press\\_releases/nr11-20-09.cfm](http://www.acog.org/from_home/publications/press_releases/nr11-20-09.cfm)

When you take them to your doctor, highlight the last sentence of

*continued on page 3*



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I am a:  DES Daughter  DES Son  Other  DES Granddaughter or Grandson  
 DES Mother of a:  Daughter  Son

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## Join OnLine Support Group for DES Daughters

Want to be in touch, via e-mail, with other DES Daughters? As a benefit of being a DES Action member you can join the DES Action Daughters On Line Support Group. That way you can ask questions and share experiences common only to those of us who are DES exposed.

To join the DES Action On Line Support Group simply send a blank e-mail to:  
[DESactionDaughters-subscribe@yahoogroups.com](mailto:DESactionDaughters-subscribe@yahoogroups.com)

You'll receive an e-mail back from Yahoo! Groups confirming your request to join. It offers two registration options and the easiest is Option 2. Click "Reply" so the note is sent back.

Once we've checked to be sure you are a current DES Action member, you'll receive a welcome to the group letter explaining how to send messages. Then you can participate in the e-mail conversations, or just quietly read and enjoy the learning experience.

### MISSION STATEMENT

The mission of DES Action USA is to identify, educate, support and advocate for DES-exposed individuals as well as educate health care professionals.



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## Potential Birth Defects in DES Grandchildren

from page 1

From the mothers of DES Granddaughters and the DES Granddaughters themselves, “the most frequently reported birth defects in daughters were skeletal and heart defects.” Both groups of defects were statistically associated with DES. Skeletal anomalies in DES Granddaughters reported by mothers “included hip dysplasia, scoliosis, clubfoot, missing limbs and extra digits; heart defects included atrial septal defect and ventricular septal defect.” The Granddaughters “self-reported skeletal anomalies included hip dysplasia and missing forearm; congenital heart conditions included heart murmur and atrial septal defect.” Hip dysplasias were the most commonly reported defect and may be due to pregnancy and birthing complications related to the mothers’ DES exposure. The higher frequency of cardiac defects in the granddaughters appears to be a result of under-reporting of these conditions by the unexposed mothers rather than a true excess in the exposed.

## New Guidelines for Paps

from page 1

paragraph four.

**It is important to note that DES Daughters should continue with annual Pap/pelvic screenings even after a hysterectomy.** While the cervix may have been removed in surgery, the vagina still needs to be examined annually for the aggressive DES-specific cancer.

There are no special gynecological screening recommendations for DES Granddaughters, (children of DES Daughters and Sons). Unless future research indicates otherwise, they do not appear to have the same cancer risk as DES Daughters. That said, they should see their doctors if they experience unusual pain or bleeding. **DES VOICE**

*Editors Note: See page 6 to learn how recently released mammography guideline changes do not affect DES Daughters either.*

Interestingly, “none of the mothers reported daughters affected by reproductive tract anomalies, including T-shaped uterus and abnormalities of the cervix, which are known to be associated with prenatal DES exposure in women.” Titus-Ernstoff goes on to state “the study population may be too young to manifest such outcomes, even if an association existed... Further study of the third generation will be needed to determine whether the reproductive tract toxicity observed in prenatally DES-exposed women occurs in their daughters.”

This study raises the possibility of a broader range of birth defect changes than previously have been reported in DES Grandchildren. It also raises questions about reporting errors from all the mothers, both those DES-exposed and not, in this data. As with any epidemiological study relying on memory to answer questions years later, there is the potential for error.

However, by reporting the responses of the participants, Titus-Ernstoff provides the endocrine disruptor research community with an oppor-

tunity to learn more about how DES may affect human health. This study is important because it comes from and

“...our data raise the possibility that the offspring of prenatally DES-exposed women may have an increased frequency of birth defects.”

is about DES Grandchildren participants, who encompass “the only study of third generation outcomes in which the prenatal DES exposure status of the mother is verified by the medical record.”

Titus-Ernstoff concludes, “... our data raise the possibility that the offspring of prenatally DES-exposed women may have an increased frequency of birth defects.”

More research is needed from the NCI DES Follow-up Study researchers, and other research communities, to add understanding on how endocrine disruptors, like DES, affect human health through the generations. **DES VOICE**

## Take Directions For A DES Daughter Pap/Pelvic Exam To Your Doctor

Most good doctors are happy to do a proper DES Daughter exam if you place the directions for doing it right into their hands. The exam is similar to a regular one but it is more comprehensive.

You can easily get a copy by going to our web site:

**www.desaction.org** and clicking the DES Daughter link on the left side of the screen. Then, in the second paragraph, entitled: Proper DES Exam (Pap/pelvic), click the link for Annual Exam (PDF). Print the one-page direction sheet to bring with you when you go for your annual appointment.

If you prefer, you can e-mail us at [info@desaction.org](mailto:info@desaction.org) and request a copy.

Or, feel free to send a self-addressed stamped envelope to the office: DES Action USA, P.O. Box 7296, Jupiter, FL, 33468. We'll mail the fact sheet right out to you.

We frequently hear that health care providers appreciate seeing this information. It also gives DES Daughters the comfortable feeling of knowing their exam is being done correctly. Be sure to have the fact sheet put in your patient file so it is readily available for your next appointment. **DES VOICE**

# YOUR VOICE

*The following article, by DES Action USA member JoAnne Bock, 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 e-mail Fran Howell at [info@desaction.org](mailto:info@desaction.org) for more information.*

## DES: Out of Necessity Comes a Special Hobby



Jo Anne Bock

### By DES Mother Jo Anne Bock as told to Fran Howell

Being allergic to citrus, I won't urge anyone to make lemonade when handed lemons. Instead, I say, "when given cherries make cherry pie." So that's what I did when my first grandchild was born. Actually, I didn't make pie — I made baby clothes.

Adrienne was three months early, and tiny. Just 4 lb., 2 oz. It wasn't a complete surprise because I'd had four miscarriages and was prescribed DES while pregnant with my daughter, Patti Jo. That put her at increased risk for premature labor. What was a shock was what one of the hospital nurses suggested. She told us to go

out and buy doll clothes for the small infant because regular infant clothes were too big. I was appalled. Doll clothes aren't meant for babies!

At a children's clothing store across from the hospital I stopped in and found nothing to fit preemies. So I started sewing.

My daughter was tickled pink when I returned to the hospital with a bonnet and gown for Adrienne. Of course, she looked adorable. When clothes fit, babies seem bigger and healthier. When clothes are too large, babies appear shrunken and lost in their outfits.

And there is something else about infant clothes made to fit the child. Ribbing around the sleeves helps keep in valuable body heat, which is lost when sleeves dangle from bitty wrists. Without preemie-sized sleeves the wee little ones have to work at maintaining their temperature, wasting energy they should put into growing.

Adrienne was the best-dressed baby in the neonatal intensive care unit. On a whim I went back to the clothing store, which agreed to sell my preemie clothes on consignment. It wasn't long before a gown and bonnet sold, and then my business

took off like wildfire. Word spread quickly and in just two months I needed to name my company.

It wasn't difficult because invariably, the first thing people say when they see a preemie is, "Oh So Small." The name stuck.

I now have eight industrial sewing machines and an outbuilding full of fabric. Through the years I've learned a few things. For example, color choices are important. Yellow tones make a jaundiced baby look worse. Aqua blue is better in that situation. Clear colors and prints are my favorites. Adaptations specifically for preemies include special Velcro fasteners and very soft cloth. Various styles include a hand mitt to keep babies from scratching their eyes, and





heel flaps to provide easy access for a pulse oxymeter to monitor oxygen levels. There also can be special cut-outs for other monitor wires.

Some of my creations are worn by the teeniest of infants. One mother needed clothes for her baby weighing just over a pound. As I sewed those outfits I made an important adjustment that has stuck. I took the bow I usually placed at the very top of the hat and sewed it on the front instead. That way it can be seen in the baby's photos and pleases mothers no end.

I'm now 80 years old and a proud Grandma. Adrienne is in her 30s and is 5' 10" tall. Her younger sister, Erin, was also born prematurely and I made sure her clothes fit, too.

I also was given DES while pregnant with my son Mike, which makes him a DES Son. He and his wife, Debi are the adoptive parents of Lilliana. She's the only one of my granddaughters who is interested in sewing!

Sewing for me is a hobby — I don't do it for money. Making preemie clothes is my passion and got me out of a slump three decades ago when a back injury forced me to give up my nursing career. I was an empty nester and depressed. Then suddenly, the negative of DES exposure threw me a curve in the form of a premature granddaughter whose needs gave my life purpose once again.

A grateful mother told me recently how much it meant to her to dress her tiny preemie baby in pretty, and properly fitting, clothes. That was a time when there was nothing else she could do for her child.

And in between sewing, when the spirit moves me, I still like making cherry pies!

You can see preemie Oh So Small baby outfits at [www.preemiestore.com](http://www.preemiestore.com). And I just got the exciting news that my preemie clothes will be worn in the March 3rd episode of TV's *Law and Order: Special Victims Unit* featuring a story line about two premature babies.

DES VOICE



## An Event Worth Attending

Come see a live staged reading of select scenes from *WONDER DRUG*, a screenplay written by DES Action USA member, and award-winning screenwriter, Caitlin McCarthy.

DES Action USA members clearly do not need to be told what the *Wonder Drug* is! McCarthy's screenplay is a scientific drama that tells our story.

### When:

- Sunday afternoon, April 18, 2010
- Doors open at 1:30 pm
- Reading takes place from 2-2:30 pm
- Question & Answer session until 3:00 pm
- Cash bar available until 4 pm with music played from The Ruse's latest CD

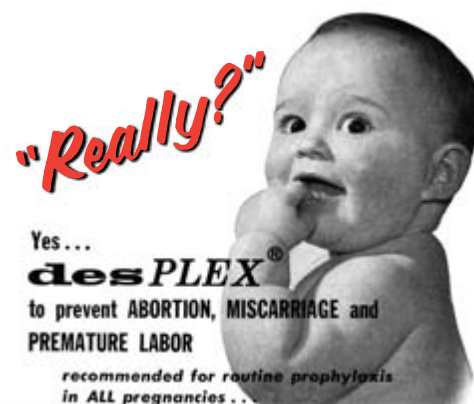
### Where:

Cinespace Los Angeles  
6356 Hollywood Blvd.  
Los Angeles, CA 90028  
(323) 817-3456

### Admission:

\$10 (cash only) with proceeds benefiting DES Action USA

Make plans to attend and see for yourself what the buzz is about surrounding this exciting script — soon to be a motion picture!



*WONDER DRUG* is a screenplay inspired by the true story of DES. Developed as a medical miracle to help women with pregnancy issues it became a cash cow for pharmaceutical companies and a tragedy for the families whose lives were touched by the drug.

McCarthy says her script delves into the consequences of having badly tested, yet FDA approved drugs on the market, and shows corruption of the drug industry that foisted DES upon an unsuspecting public.

Set in Boston, *WONDER DRUG* interweaves the lives of a Big Pharma executive, feminist doctor, and thirty-something newlywed across different decades.

DES VOICE

# What DES Daughters Should Know About Mammograms

By Fran Howell

New mammography recommendations released recently by the U.S. Prevention Services Task Force (USPSTF) raised quite a stir. This government panel calls for starting mammograms at age 50 (not 40, as is the current guideline) and every two years thereafter for women with no elevated breast cancer risk.

**But research suggests DES Daughters are at increased risk for the disease from age 40 on, so DES Action USA believes yearly mammograms beginning at that age are appropriate for DES Daughters.**

Cumulative exposure to mammography radiation is a risk, though.

Radiation, which is known to cause breast cancer, accumulates in women's bodies through the years, because it is not eliminated. What hasn't been conclusively determined is how much risk mammography radiation poses.

The American Cancer Society (ACS) says the level of radiation from mammography does not significantly increase the breast cancer risk for those who get regular mammograms.


According to the ACS, women who have yearly mammograms beginning at age 40 and continuing until age 90 will get a total of 20 to 40 rads. A rad is a measure of radiation dose. To put radiation dosages into perspective, the ACS and many other experts, maintain that the amount women receive from screening mammograms is about the same as what we are all exposed to in our natural surroundings (background radiation) over a period of about three months.

For DES Daughters, the benefit of early detection seems to outweigh the radiation risk. Mammograms are

the current standard for breast cancer detection with no other risk-free diagnostic devices available at this time.

DES Action USA Co-Founder Pat Cody calls for a major push to develop new, safer, and effective breast screening tools to replace mammograms. According to Cody, "It is appalling such a device has not yet been developed."

"As always," she says, "It boils

down to the familiar 'risk versus benefit' equation. Given what research tells us, it seems to me that DES Daughters should be vigilant about having annual mammograms starting at age 40, even knowing the radiation exposure risk." Cody also stresses the importance of doing monthly breast self-exams and reporting unusual lumps to doctors. 

## Debunking a Mammogram Misconception

Mammograms do not prevent breast cancer. That's what an RN working in the field of breast cancer diagnostics reminded participants on the **DES Daughter On Line Support Group** listserv (see page 2 for information on joining).

As a DES Daughter, and a DES Action USA member, Jennifer Bailer's expertise was welcome during discussions about mammography. One point she made was that a mammogram is nothing more than a diagnostic tool.

She told the group, "When you have a mammogram you are not 'good to go' for a year. You can have a normal mammogram on Oct. 1 and develop a lump on Oct. 2. All a mammogram does is tell a woman that at that particular point in time there was nothing in her breast that looked like it might be cancerous. That's all."

Bailer says mammography doesn't predict the future and cer-

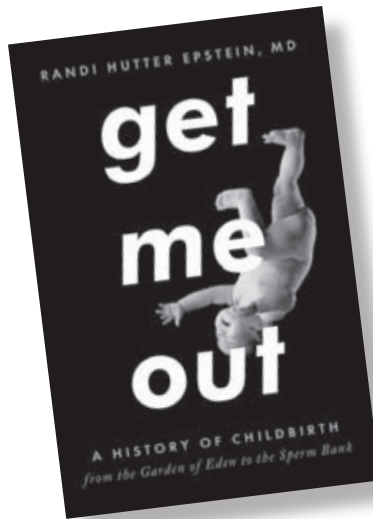
tainly doesn't prevent anything. And it does come with risks. But so does not having an annual screening, especially if you are at increased risk for breast cancer. "In my work I see women every day who were diagnosed between ages 40-49 with the disease via mammogram. I have seen women between 20-39 years old who find lumps on self-exams, come in for mammograms and end up with mastectomies. Thankfully, that is rare." But at least these women can start their treatments, hopefully soon enough to make a difference.

Bottom line says Bailer, "Women need to know the strengths and limitations of mammography and make their decision about the screening based on their personal risk factors and input from their health care providers. Mammograms are not perfect. They are not 100% effective, but they are the best way to detect breast cancer that we have at the moment."



# An Excellent Historical Review of Childbirth Includes a DES Chapter

*Get Me Out: A History of Childbirth from the Garden of Eden to the Sperm Bank*, by Randi Hutter Epstein M.D., W.W. Norton, 2010, \$24.95.



Epstein tells of 1950s practitioners such as Grantly Dick-Read and “natural” childbirth, Ferdinand Lamaze and his breathing techniques (your

reviewer experienced both of these approaches). One chapter “Toxic Advice and a Deadly Drug: DES” describes the story we know from our own lives. She concludes:

“Some say the drug itself changed the nature of the patient-gynecologist relationship, crystallizing and politicizing anger brewing among American women.”

We know that is true: the DES story has helped make women more active participants in their own care. We still have challenges; Epstein reminds us, in her final chapter:

“Pregnancy and childbirth — however you get there — is one of the few adventures you will ever embark on that when you finally get to the finish line, you’ve only just begun.” **DES VOICE**

## Large New Study Considers DES Links to Breast Cancer

By Kari Christianson

A major breast cancer research study will ask participants whether they have been exposed to DES. Fifty thousand women are part of the Sister Study, so the size of this group is considered large enough to give researchers meaningful information into the causes of breast cancer, including, potentially, prenatal DES exposure.

The Sister Study, a ten-year long research project of the National Institute of Environmental Health Sciences (NIEHS), is focusing on environmental and genetic factors. The 50,000 participants are sisters of women who have had breast cancer.

The Principal Investigator is Dale Sandler, Ph.D., Chief of the Epidemiology Branch at NIEHS. She says researchers hope to identify clues as to what causes breast cancer by compar-

ing women who develop it with those who remain disease-free.

Additionally, a group of women who had breast cancer before the age of 50 is being assembled in order to focus on early onset breast cancer. Breast cancer survivor sisters of current Sister Study participants are being invited to join what is called the Two Sister Study. The NIEHS is working to enroll up to 2,000 women for this aspect of the research.

The large Sister Study itself will be an opportunity to understand how, and if, environmental exposures to hormonally active substances, including DES, affect breast cancer rates. The study includes women of different ethnic, education and employment backgrounds, as well as a variety of ages.

DES Action USA actively seeks to have questions regarding DES expo-

sure included in health history data collected for major studies, as well as on all health history forms. As part of our commitment to research, our organization is a member of the NIEHS Public Interest Partners, which works to improve communication and information sharing between consumer groups and researchers. I represented our organization last December when Sandler provided a Sisters Study update and confirmed that a question about prenatal DES exposure is included in the study’s health history questionnaire.

For the DES community this breast cancer study is another important research venue, in addition to the National Cancer Institute’s ongoing DES Follow-up Study.

To learn more about the Sister Study and the Two Sister Study, visit [www.sisterstudy.org](http://www.sisterstudy.org). **DES VOICE**

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## DES On The Internet—A DES Daughter Shares Her Story

**By Fran Howell**

On a daily basis I check in with a blog diary being written by DES Action USA member, Mary Katherine Kennedy. She is chronicling her life since successful fertility treatments last summer. I find it fascinating and urge you to join me as her story unfolds. [www.mkkennedy.com](http://www.mkkennedy.com)



Mary Katherine Kennedy

I began reading right about the time Kennedy learned she

was pregnant with twins. I've followed her through the emotional trauma of losing one, hanging on to the other, and nearly going into preterm labor. Now she is on complete bed rest, which is particularly trying for such an active and engaged individual.

What draws me to Kennedy's blog is her ability to so eloquently express her feelings. It is full of emotions familiar to many of us who are DES-exposed. But I could never adequately describe them the way she does. There are worries, insecurities, nagging fears and questions that arise with every bump in the road along the way to growing her family.

One of Kennedy's goals is gen-

erating awareness of DES. "If I had known about my exposure before last summer, I would not have unknowingly subjected myself to additional estrogen for 25 years in birth control pills. And I would have done a more thorough risk/benefit assessment before undergoing my seven medicated cycles of intrauterine insemination and IVF."

Kennedy's blogs are unflinchingly honest. They share the details of her T-shaped uterus and the struggles of her high-risk pregnancy. "I hope my candor helps readers realize they are not alone."

Reading her extremely well written and gripping posts is a window into the debris filled landscape of DES exposure.

**DES VOICE**