

How a DES Daughter is Going HRT-Free .....4  
 Remembering A Special Woman Who Put DES In the National Conversation.....6  
 Proof DES Prescribed Not Just For Problem Pregnancies.....7

## DES Action Health Survey Overview

### Results From Our Second Survey; More In Future VOICE Issues

In 1985, DES Action asked VOICE subscribers and other DES-exposed people to complete a questionnaire about various health problems they may have experienced. Approximately 1,700 people (Mothers, Daughters and Sons) responded back then. Many conditions already known, or suspected to be associated with DES exposure, were reported in high numbers. In addition, it appeared that DES exposed individuals reported more diseases that were associated with immune dysfunction, including asthma, arthritis and lupus. (VOICE #27, Winter 1986) This association was confirmed by subsequent studies by scientists and medical researchers. (Noller, KL et al: Increased occurrence of autoimmune disease among women exposed in utero to diethylstilbestrol. *Fertility & Sterility* 1988; 49-1080-2.)

In addition to the Winter 1986 issue of the VOICE, the findings of the earlier DES Health History Survey were published in two peer-reviewed journals: Wingard DL, Turiel J: Long-term effects of exposure to Diethylstilbestrol. *Western Journal of Medicine* 1988; 149:551-4; Turiel J, Wingard DL: Immune response in DES-exposed women. *Fertility & Sterility* 1988; 49(5):928-9.

While surveys such as these cannot definitively prove an association, they do provide clues about areas where more rigorous research is needed. Given that most DES Daughters and Sons are now past childbearing and potentially facing new health challenges, and little is known about DES Grand-

daughters and Grandsons, some of whom are now attempting pregnancy, the DES Action Board felt that a new survey might prove informative.

With the help of Dr. Deborah Wingard of the University of California San Diego School of Medicine, an updated survey was conducted in 2012. Approximately 1,200 people responded either by mail or by the

Internet, including 1,019 from the United States, 143 from Australia, 33 from Europe, 17 from Canada and 19 from other areas (or unstated).

This is the first of several articles, which will share results of the survey. We will begin by focusing on respondents from the United States. The questionnaires provided information about 98 DES Mothers, 775 DES Daughters and 72 DES Sons, as well as 52 DES Granddaughters and 22 DES Grandsons. Among these respondents from the United States, 93% (950) knew for sure that they were DES-exposed; 58% (587) had tried to obtain their medical records, of which 53% (311) had been successful. The average age of respondents was 78 years for Mothers, 56 years for Daughters, 55 for Sons, 28 for Granddaughters and 22 for Grandsons. Approximately 96% were Caucasian.

### Immune System Issues Need More Attention

#### Of Particular Interest are Asthma and Lupus

Diseases related to the immune system were again reported in higher numbers than expected. For example, 10% of DES Daughters reported having ever been diagnosed with asthma in 1985 compared to 19% in 2012. According to the CDC, only 7% of women 40-70 years old report having ever been told they had asthma. Note that Daughters were 14-44 years old in 1985 and 41-71 in 2012, so some of the increase may be due to additional cases occurring over time. Alternatively, this could reflect increased awareness given publicity about the first

*continued on page 3*

**“While surveys such as these cannot definitively prove an association, they do provide clues about areas where more rigorous research is needed.”**

It is important to remember that members of DES Action, and those who would respond to a survey about DES exposure, may not be typical of all DES-exposed women and men. Individuals who contact DES Action are more likely to have experienced some

*continued on page 3*



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**Yes!—I want to join DES Action to stay informed and support a cause I believe in.**

All members receive **The DES Action Voice** quarterly. Those at the **\$100 level and above receive an annual report on DES Action's work and progress.** All contributions are **tax deductible.**

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Please make checks payable to **DES Action.**

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

NAME

ADDRESS

CITY | STATE | ZIP

PHONE

E-MAIL ADDRESS

## 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: [DESactionDaughters-subscribe@yahoo.com](mailto:DESactionDaughters-subscribe@yahoo.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.

## Have You Considered Planned Giving?

Think about including DES Action USA in your estate planning, trusts and wills. Speak with your estate planning attorney to ensure your wishes are correctly put in place.

Follow DES Action USA on:



### MISSION STATEMENT

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



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## Health Survey Overview

*continued from page 1*

kind of health problem that may or may not be related to their exposure to DES. Also, those who have had health problems are more likely to complete a survey than those with no health problems. Many of the conditions listed on the questionnaire may not be related to DES exposure. However, if conditions are reported more often than expected, these may be areas that the scientific community should explore in a more representative group, such as the National Cancer Institute DES Follow-up

DES Mothers	
Breast Cancer	28%
DES Daughters	
Adenosis	45%
T-Shaped Uterus	42%
Cervical Anomalies	52%
Miscarriages	35%
Ectopic Pregnancies	12%
Infertility	48%
Dysplasia	34%
Breast Cancer	11%
CCA (vagina or cervix)	3-5%
DES Sons	
Undescended Testicles	22%
Epididymal Cysts	31%
Low Sperm Count	31%
Poor Sperm Quality	25%

## Immune System Issues

*continued from page 1*

survey results and subsequent research.


Among DES Sons, 15% reported asthma in both surveys; the CDC reports that only 4% of men 40-70 years old have ever been told they had asthma.

Other diseases related to the immune system include arthritis (5% of Daughters, 7% of Sons), diabetes (6% of Daughters, 10% of Sons), and lupus (2% of both Daughters and Sons). The latter again being higher than expected for this age group.

This survey included a question that asked respondents to list other autoim-

Study (formerly the DESAD study).

As in the first survey, many conditions already known, or suspected to be associated with DES exposure, were reported in high numbers. For example, among DES Daughters who responded, 45% reported adenosis, 42% T-shaped uterus, and 52% cervical anomalies such as hoods or ridges, 35% miscarriages, 12% ectopic pregnancies, 48% infertility, 34% dysplasia, 11% breast cancer and 3-5% clear cell cancer of the vagina or cervix. For some of these, i.e. clear cell cancer, the number is higher than expected even for the DES-exposed. This is an example of reporting bias—those with health problems are more likely to respond to surveys. Among DES Sons who responded, 22% reported undescended testicles, 31% epididymal cysts, 31% low sperm count and 25% poor sperm quality. Twenty-eight percent of DES Mothers reported breast cancer.

Watch for future articles where we will explore in more detail the responses of DES Mothers, Daughters and Sons to our recent survey, as well as Granddaughters and Grandsons, and a comparison of results from the United States and other countries. Thanks to everyone who completed the survey, which may provide clues to scientists who are investigating the long-term health consequences of DES exposure! 

immune conditions they experienced, in an effort to see if any rare condition was appearing particularly frequently. Responses included (but are not limited to) fibromyalgia, Sjogren's Syndrome, scleroderma, chronic fatigue syndrome, Hashimoto's Thyroiditis, eczema, Myasthenia Gravis, and colitis.

Please keep in mind that many of these conditions may not be related to DES exposure. Some of the diseases would be expected in a group of individuals of this age group.

Interestingly, in 2010 the NCI DES Follow-up Study reported that no link was found between autoimmune disorders and DES exposure, with the exception of rheumatoid arthritis. This


## Online Back to School Shopping Benefits DES Action USA

What could be easier? When shopping online start first at [www.GoodShop.com](http://www.GoodShop.com) and designate DES Action USA. We get a donation for each purchase you make—at no cost to you.

The list of stores with back to school items is amazing and includes Amazon, Apple, Bed Bath and Beyond, Staples, Target, L.L. Bean, Macy's and many more. There are hundreds to choose from.

Use [GoodShop.com](http://GoodShop.com) to get to a retailer's site. Then shop as usual. Please try it, and ask family and friends to support us, too. It's easy! We received a whopping \$182.07 donation last year from [GoodShop.com](http://GoodShop.com) thanks to your help. It works and adds up. Thank you!

2010 study followed the same women in the 1988 study. However, as the cohorts aged, autoimmune disorders were reported more frequently by unexposed participants than by the DES-exposed. Reports of newly diagnosed autoimmune disorders among DES-exposed women dropped, perhaps because DES Daughters may have been diagnosed at earlier ages.

Only carefully controlled research can confirm any association between DES and autoimmune diseases. We will be sharing our survey results with scientific colleagues who are interested in hearing of health problems being experienced in the DES-exposed community. 

# YOUR VOICE

*This article, by DES Action USA member Carol O'Leary, 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](mailto:info@desaction.org) for more information about submitting it.*

I decided to age naturally after watching my mother age. She was prescribed the synthetic estrogen Premarin, following radiation therapy for Hodgkin's disease, which put her into early menopause. The Premarin gave her endometrial cancer.

Given my DES exposure, and my mother's cancer, I wanted to avoid more hormonal exposures.

On the other hand—and please let me be brutally honest—I wanted to keep my 'girl parts' in working order. Vaginal dryness is a vexing problem for so many of us. So I started my search for products to moisturize and lubricate without the carcinogenic ingredient Paraben, which is added to personal care products to combat bacteria and mold. But the last thing I need is a carcinogen in the vaginal area.

I found most products at my local chain drugstore were, as they say in Britain, 'rubbish.' KY is messy and contains estrogen-mimicking parabens. Replens is made with glycerin, which caused repeated yeast infections until I put two and two together and realized that by using this lubricant I was putting sugar inside to feed the yeast. My doctor didn't even make the connection.

So I knew I'd have to go it alone. It was clear that asking doctors isn't much help. They know only name brand products they learned about in medical school—or that drug representatives promote to them.

I've learned a lot along the way on my own and I'm pleased with the results. Since I'm frequently asked about aging without hormone replacement therapy, I'll share with you what works for me. I don't endorse or sell

any of this. I'm just sharing information that may be useful for those of us who don't want to start using HRT or who want to ease off it.

A good place to start is a website recommended by another participant on our DES Action DES Daughter Online Support Group listserv. A Woman's Touch ([www.a-womans-touch.com](http://www.a-womans-touch.com)) is a store for women's health and sexuality run by two female gynecologists. They have an interesting vaginal renewal program and kit (\$50) that consists of lubricant, a vibrating wand and massage as an alternative to estrogen for menopausal dryness.

Another product to consider is Sliquid ([sliquid.com](http://sliquid.com)), for use as a lubricant/moisturizer. It's paraben and glycerin free. At the A Womans-Touch site is an applicator that works well. And drugstore.com has Sliquid singles that can be slipped into your purse next to a condom for use as needed when vaginal dryness might be an issue.

When my gynecologist advised me to 'use it or lose it' to maintain the health of my sexual system, I began looking into these products. Frankly, given my staunch Irish Catholic background, it wasn't easy to start. I carefully read all the directions to figure out how to use everything. My friends joke that I'm so naive they claim I grew up inside a closet in Boston, not in a neighborhood. So you can see this was a huge step for me. But I was de-

termined to deal with vaginal dryness without HRT, and it's working!

Of note is that for those with a partner the recommendation is to continue, or increase your intimate sessions to keep things moist. That's where knowing about moisturizers and lubricants really helps, especially after age 50.

The staff at [www.a-womans-touch.com](http://www.a-womans-touch.com) and [sliquid.com](http://sliquid.com) are very helpful. A Woman's Touch has downloadable brochures with information on sexual health as we age, along with information on sexuality after cancer, too.

For external dryness while exercising I've had awesome luck with the anti-chafing 'Soothing Care Powder Gel' from Monistat. Made with silicone, it keeps me from getting chafed when I do hours of Zumba dancing.

I was uncomfortable at first learning about negotiating life without HRT. I had to make decisions about an area of my body to which I hadn't previously given much thought. Now I hope what I've shared here will get you going, too. Options exist for all women, and especially for DES Mothers, Daughters and down the road DES Granddaughters who wish to avoid, or decrease, extra hormonal exposures. These are just a few. When you look you'll find the ones that work best for you. Make yourself a little kit and then go about enjoying life to the fullest.



# Researchers Learn from the DES Experience

## Focus is on Prenatal Exposures Harming Adult Health

By Kari Christianson

DES is a powerful endocrine disrupting chemical. We know firsthand.

No report about endocrine disrupting chemicals (EDCs) is complete, nor can it even begin, without listing the known adverse effects of prenatal exposure to diethylstilbestrol, DES. *The State of the Science of Endocrine Disrupting Chemicals—2012* is no exception. The United Nations Environmental Programme (UNEP) and the World Health Organization (WHO) produced the document in collaboration with international experts.

This massive report (293 pages) names close to 800 chemicals that are known or suspected to be hormonally active. These chemicals have the potential to harm human health and fertility. To date only a small fraction has been studied.

In a Consensus Statement published in the April 2013 issue of *Environmental Health Perspectives* (EHP) a group of researchers from around the world offer a concise summary of the report. They recognize that identified endocrine disruptors, like DES, are only the “tip of the iceberg” in finding and understanding the complexity of an array of chemicals and interactions in our environment. New testing and evaluation methods, as well as international cooperation, are needed.

In an editorial accompanying the EHP article, Linda Birnbaum, Director of the National Institute of Environment Health Sciences (NIEHS) and the National Toxicology Program (NTP), provides additional insight. “Taking the animal and human evidence together, the report demonstrates a strong likeli-

hood that exposure to EDCs during fetal life and/or puberty plays a role in the proliferation of male and female reproductive problems, endocrine-related concerns, infections, asthma, obesity, diabetes, and behavioral and learning disabilities, including attention deficit/hyperactivity disorder (ADHD).”

Birnbaum continues, “Over the last 10 years, the focus of EDC research has shifted from investigating adult exposure and disease outcomes to examining developmental exposure and later-life disease outcomes. This latter approach is now considered the most appropriate approach for most endocrine-related disease/disorders (U.S. Environmental Protection Agency 2012).”

U.S. researchers have been studying DES-caused adverse health outcomes from prenatal/developmental exposure for over 40 years. And the DES-exposed community continues to experience adverse effects from a synthetic hormone given to our mothers during pregnancy. DES has been linked to our reproductive tract structural changes, fertility concerns and adverse health experiences, including cancer.

It’s hopeful that researchers around the world are recognizing that in order to prevent future human disease, prenatal exposures must be reduced. And while new methodology to study all potential endocrine disruptors is needed to prevent future harm, DES Action will continue to advocate for DES research. On-going study of DES exposure is still providing new information about adverse effects of prenatal and generational exposure to EDCs.

 **DES VOICE**

# Empowering DES Daughters

## Toolkit Coming Soon!

You do everything right. You tell your doctor that as a DES Daughter you need a special DES Daughter Pap/pelvic exam—and you get a nod. Does the doctor really know how to do it? You wonder. Then you remind your provider you need the exam done every year and now you get an argument. “New guidelines say women can skip years...”

That leaves you having to explain about the proper health screenings identified for DES Daughters and you could use some help.

So DES Action USA is developing a **DES Daughter Toolkit** designed specifically for our health care providers. It will bring together information from the Centers for Disease Control and Prevention (CDC), the U.S. Preventive Services Task Force (USPSTF) and the National Cancer Institute DES Daughter Follow-up Study via the *New England Journal of Medicine*. These are resources doctors and other health care providers trust.

No longer will it be your word against the limited DES knowledge most doctors have—even well meaning ones. *Feel empowered—hand the Toolkit to your doctor and let it do the talking for you.*

The information in it isn’t new and already is available. But the **Toolkit** will pull it all together and package it in a professional and useful format for doctors to easily read and understand.

Our **DES Daughter Toolkit** will be in the next VOICE newsletter, so watch for it in November. It’s an exciting and useful new benefit of DES Action membership!

# REMEMBERING AN EFFECTIVE WOMEN'S HEALTH ADVOCATE

## Barbara Brenner Put DES Into Breast Cancer Conversations

By Kari Christianson  
and Fran Howell

We knew early on she was sick. During dinner one evening, she confided in us of her diagnosis of ALS (amyotrophic lateral sclerosis) and how she was acutely aware of what was coming. Brenner's sister died from the ravages of this awful disease, so the diagnosis was chilling. But her admission was almost an afterthought. Brenner wouldn't let the conversation linger there. Instead, she wanted to pursue ideas for tackling the wrongs of our profit driven health care system, which allows corporations, like drug companies, to benefit mightily from illness—with little government regulation.

It's no accident that DES Action and Breast Cancer Action (BCA) share a "last" name. Both emerged from the Bay Area cauldron of grassroots health care activism. As BCA's Executive Director, Brenner seized every opportunity to mention DES in describing the endocrine disruptor link to breast cancer. She staunchly demanded research into causes and



prevention of the disease. Brenner was 41 when first diagnosed with breast cancer.


Taking a cue from DES Action, which has never accepted funding from drug makers, BCA was one of the first and few breast cancer groups to refuse money from corporations that profit from cancer or contribute to it by polluting the environment.

Prevention First: A Coalition of Independent Health Organizations was another Brenner idea. In addition to Breast Cancer Action and DES Action, she recruited six other

organizations in the U.S. and Canada that don't take corporate or pharmaceutical money to speak out against the proliferation of direct to consumer advertising of prescription drugs. As the 2002 brochure stated, "Drug Ads Have Nasty Side Effects." Adverse health outcomes made DES the living example of the problem with misleading and false advertising.

Brenner was remarkably gutsy, articulate and passionate. She relished her image as a 'Bad Girl of Breast Cancer,' who thrived on shaking up the status quo.

We gave Brenner one of our DES Action Bad Karma for Big Pharma t-shirts, which pleased her no end. She wore it to events and surprised us once by wearing it when we went to lunch together.

It's difficult to believe Brenner is no longer with us; her powerful advocacy around women's health issues resonates still. She relished speaking truth to power and making a difference. We honor Brenner's memory by keeping up the good fight with our DES Action efforts. 

## Interesting Finding Regarding DES Daughter Mammography Rates After Link Found to DES Breast Cancer

"Mammography Screening Behaviors of Women Exposed Prenatally to Diethylstilbestrol," Elizabeth A. Camp et al., *Journal of Women's Health*, Volume 21, Number 2, 2012.

Reviewed by Kari Christianson

A preliminary study connecting prenatal DES exposure with an increased risk for breast cancer in DES Daughters over age 40 was published

in 2002.

DES Follow-up Study researchers combed data to see if this information changed behavior regarding DES Daughter mammography rates.

According to researcher Elizabeth Camp, MSPH, from the University of Texas Health Science Center in Houston, there was statistically no difference in the screening rates of DES Daughters (73.8%) and unexposed participants (74.0%) in the study. They

both reported having more than three mammograms between the years 2001 – 2006.

But that is a higher rate than the national average. Camp suggests this may be due to socioeconomic status, more regular doctor visits, or an observed knowledge of cancer risk by the unexposed sisters of DES-exposed women who make up 12.1% of the unexposed participants in the Na-

*continued next page*

# DES Not Just Prescribed for Problem Pregnancies

*The Drug Was Promoted For Use By All Pregnant Women*

By Kari Christianson

It is commonly understood that DES prescriptions were written to prevent miscarriage either because of medical concerns in a pregnancy or because of a previous miscarriage. What isn't as well known is that drug companies promoted more routine use of DES for all pregnant women.

When the question of DES prescribing for prophylactic reasons arose, I relished the opportunity to comb through DES Action's archives to find a study with the exact language. The trail took me to a 1954 article published by researchers George and Olive Smith in *Obstetrics & Gynecology*, Vol. 4, No. 2.

With pharmaceutical industry funding these Harvard scientists were ardent proponents of DES. They developed the dosing strategy that bears their name, the Smith and Smith regimen. It recommended starting with 5 mg per day of DES and ending in the 35<sup>th</sup> week of pregnancy with a whopping 125 mg per day.

The timing of this article, "Prophylactic Hormone Therapy," is interesting—coming shortly after two journal research papers published in 1953 by William Dieckmann and James Ferguson that showed DES did

not work to prevent miscarriage. It appears the Smiths' paper was written to refute those articles.

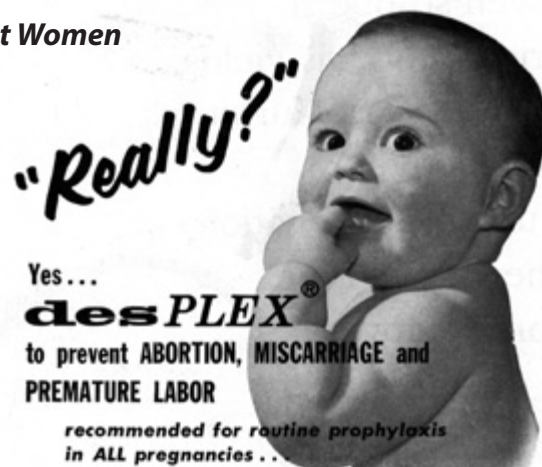
While they state in the first paragraph that DES is to be administered in selected cases, they also cite here and in other articles in the bibliography that in their studies DES was administered to women during their first pregnancy. They state that they studied first pregnancy women, "Because primigravidas have a relatively high incidence of late-pregnancy complications.... Although therapy failed to forestall premature delivery, the incidence of infants premature by the criterion of weight was less. The babies were healthier and longer, and fetal loss from prematurity was reduced."

This information was relayed stridently, and often, to doctors to promote their prescribing of DES. The Harvard researchers were well respected and the tactic worked. The findings of researchers Dieckmann and Ferguson, showing that DES given during pregnancy was no more effective than a placebo in preventing miscarriage and preeclampsia, were discounted.

Respected Women's Health Journalist Barbara Seaman, in her book *The Greatest Experiment Ever Performed*

Because the rate of mammograms was similar among the DES-exposed and unexposed women in her study, Camp concludes that DES exposure was "not a significant factor in complying with mammography screening policy."

However, the big question is whether DES Daughter mammography rates will increase as the study continues into the years past 2006. That's when NCI researchers made a more conclusive finding that DES exposure causes breast cancer, and the



on *Women*, mentions on page 37 that a doctor in Houston, Karl John Karnaky, was "the first to use DES widely to 'prevent miscarriages.' Dodds (Sir Charles Dodds, who developed DES) was concerned and sent Karnaky a study that he himself had performed, showing that in rabbits and rats, the drug (DES) *caused* miscarriages. That never stopped Karnaky, who as an old man boasted that he had given DES to 150,000 women."

So, it would seem, based on these early articles and practices publicized within the medical community, that DES was given "routinely," even to women without a history of previous miscarriage or pre-existing conditions.

As the 1957 Healthy Baby ad shows, advertising extolled the prophylactic use of DES in all pregnancies.

DES VOICE

## DES Daughter Mammogram Rates *continued from page 6*

tional Cancer Institute (NCI) DES Follow-up Study. Physician recommendation of mammography screening is also a motivating factor.

"Perception of breast cancer health beliefs has a direct effect on behavior regarding mammography use. Personalized views of risk, worry, a family history of breast cancer, and the lack of mammography access affect mammography compliance," Camp says.

DES breast cancer trial drew massive publicity and raised awareness.

Camp explains that, "Further studies would be useful to understand how DES-exposed women perceive their risk of various cancers, information that well may provide more insight into their reasoning behind compliance with recommended screenings, and to generalize how known familial and environmental predisposition, real or hypothetical, influence women's healthcare decisions."

DES VOICE

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For 35 Years!**

## *Would You Touch DES Pills Today?*

On occasion we hear from those whose veterinarians have prescribed DES to treat incontinence in their dogs. They often express having a queasy feeling when handling this veterinary medication.

But what about holding DES pills actually prescribed to pregnant woman back in the day?

Thanks to the donation from a DES Action USA member of an Eli Lilly DES pill bottle still containing pills, some DES Daughters were faced with the decision: touch or not touch. Some did and some didn't.

Here are random thoughts about coming face to face with DES:

- I'll touch the pills. They're part of me and my medical history.
- NO, absolutely not! I don't want to touch the pills. They did me so much harm and cause me worry now for my children.
- It wouldn't bother me, but I just don't feel the need to handle those DES pills.
- I want to touch them. I'm curious what they feel like.
- Now I'm wondering how my mother would react if given this opportunity. Fear? Anger?
- Tiny but deadly!

