

DES Was Prescribed After 1971

Those Exposed Despite FDA Warning Are Often Not Believed

By Fran Howell

Things were going incredibly well for 30-year old Shannon Phillips in March 2003. She had just celebrated her birthday, had moved into her own apartment and started dating a wonderful guy who eventually became her husband.



Shannon Phillips

So there was no real concern when, during a routine pelvic exam, her doctor removed a cervical polyp and biopsied it. But when he called with the results, Phillips remembers that, “even he sounded surprised.” She had clear cell adenocarcinoma (CCA) of the cervix.

That led her to an Internet search where she first learned about DES. But Phillips was born in 1973 and everything she read said that in the United States the FDA banned DES in 1971. Was that true?

Her suspicions were aroused when her mother called the doctor's office for her records and was told it should not be a problem. But, when the receptionist returned to the line, her demeanor changed to cold and perfunctory as she reported the records were not available after all.

Phillips' mother had been prescribed prenatal vitamins. The hyster-

ectomy revealed that Phillips also had a T-shaped uterus. It was starting to add up — except for her birth date of 1973.

According to Dr. Ken Noller, Professor and Chair of Obstetrics and Gynecology at Tufts University, there are, without a doubt, DES Daughters and Sons who were born after 1971. “As you know, the FDA did not ban DES. Rather, it was contraindicated for use in pregnancy,” he says. “Some doctors in 1972 and 1973 may simply not have gotten the message.”

But then there were others who

egregiously continued prescribing DES into the early 1980s, knowing full well they were going against the FDA's recommendation. Noller gets noticeably angry, even 20 years later, when he recalls a conversation with a North Dakota doctor, who arrogantly told him that DES worked (*not true*) with his patients for 40 years and that he was still prescribing it because it did no harm.

The reason Noller made the call to the doctor was because he had just seen a teenaged DES Daughter in his

continued on page 3

A Top National Scientist Understands the Dangers of Prenatal Exposures

The Head of NIEHS Sees Generational Concerns as a Research Interest

By Fran Howell

As scientists zero in on how DES causes harm to a developing fetus, they are expanding their knowledge about a new science called “epigenetics.” It is the field of study that examines how drugs, chemicals and pollutants can change the way genes function and thereby put individuals at risk for diseases years after exposure.

An excellent article by Bette Hileman in the August 3, 2009, *Environmental Health News* describes a recent two-day workshop which brought together scientists to discuss what

they are learning and what to do with this new knowledge.

While not speaking directly about DES, Linda S. Birnbaum, Ph.D., the Director of the National Institute of Environmental Health Sciences (NIEHS) made comments that show she understands concerns in the DES community.

She described how prenatal exposure to substances known to mutate the functioning of genes can “lead to increased susceptibility to disease.” Birnbaum added, “The susceptibility persists long after the exposure is gone, even decades later. Glands, or-

continued on page 3



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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

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

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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DES Was Prescribed After 1971 from page 1

office who had been born in the mid-1970's. Her mother had seen that doctor for her obstetric care.

"Fortunately, it was a rare case, but I am sure there were other U.S. doctors who thought they knew more than the FDA and ignored the warnings," Noller says. "Luckily, by 1971 most doctors had already switched to other problem pregnancy protocols and DES use had significantly tapered off by then."

DES was included in prenatal vitamin formulations, and it is possible supplies with the drug in them were

prescribed after 1971, until they ran out.

Dealing with a rare cancer was difficult enough, but for Phillips, having doctors tell her she cannot be a DES Daughter, because she was "born too late," is unbelievably frustrating. It adds insult to injury. "I want to scream at them but that just reinforces their belief that it is all in my head," she says. "It is humiliating."

Dr. Noller understands and is realistic enough to recognize that some doctors will just refuse to listen. His advice for all who were exposed to DES, whether before or after 1971, is

to stay informed. "Know the health screenings you need and advocate for them." He adds, "Those born after 1971 should attempt to get their mother's medical records. They could possibly still be around."

While not available in her case, Phillips says, "the diagnosis of CCA, along with her T-shaped uterus, leave no doubt I am a DES Daughter — now cancer-free for six years. But in the future perhaps my doctors will not so readily dismiss and humiliate other women who tell them they are DES Daughters born after 1971. We are out there and should be believed." **DES VOICE**

Top Scientist Understands the Dangers of Prenatal Exposure from page 1

gans, and systems can be permanently altered."

The NIEHS, which Birnbaum heads, has been a leader in studying DES exposure, using the mouse model. This research through the years has been vital in understanding and predicting future negative health outcomes for DES Daughters, Sons and Grandchildren.

DES Action USA Program Director Kari Christianson says, "It is particularly hopeful to hear that the new Director of the NIEHS is fully attuned to negative adult health outcomes caused by prenatal and early life exposures. We hope there will be more DES research at the NIEHS, particularly to help identify any potential health concerns among future generations, the children and grandchildren of DES Daughters and Sons."

NIEHS's Birnbaum understands the importance of epigenetic research: she said, "There is a huge potential impact from these exposures, partly because the changes may be inherited across generations. You may be affected by what your mother and grandmother were exposed to during pregnancy."

In an interview with *Environmental Health News*, Birnbaum stressed that "the current environment may not be the crucial factor to consider when ex-

"...changes may be inherited across generations. You may be affected by what your mother and grandmother were exposed to during pregnancy."

amining what causes diseases."

"Asking heart attack victims what they ate this year or last may be far less important than what they were ex-

posed to in the womb and shortly after birth," she said.

DES Action is a member of the NIEHS Public Interest Partners, which is a coalition of grassroots advocacy organizations that support environmental health research. This December, members will meet with Dr. Birnbaum to learn about current NIEHS research and discuss hopes for the future direction of studies there. DES Action's Christianson says, "Epigenetics and DES exposure will be a focus of our time with Dr. Birnbaum." **DES VOICE**

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New Brochure For DES Grandchildren

We have developed a brochure written specifically for DES Grandchildren. It is designed to help them understand DES and begin thinking about it as part of their health histories. Having accurate and current information is important.

National Cancer Institute DES Follow Up-Study researchers are paying serious attention to this group. A new questionnaire to DES Granddaughter participants went out earlier this year and data is being analyzed. We will share study results with you as soon as they are available.

If you would like to view the brochure please visit our web site at www.desaction.org and click the link for DES Grandchild.

The following is the text from the brochure.

If You Are A DES Granddaughter Or DES Grandson, You Are Not Alone

Find Out About DES Exposure

What Is DES?

DES (diethylstilbestrol) is a synthetic estrogen given to millions of pregnant women, primarily from 1938-1971, but certainly not limited to those years. In some cases DES prescriptions were written into the 1980s in the U.S. and other countries in the mistaken belief it prevented miscarriage and ensured a healthy pregnancy.

DES was given if a woman had a previous miscarriage, diabetes, or a problem pregnancy with bleeding, threatened miscarriage or premature labor.

DES was prescribed primarily in pill form, although some women did receive DES by injection. It was also included in some prenatal vitamins.

There may be no obvious signs of DES exposure. Women given DES (DES Mothers), and the children they carried (DES Daughters and DES Sons), are at risk for certain health problems. This important fact should

be a part of their health histories.

The offspring of DES Daughters and Sons are called DES Grandchildren.

What Is The Concern For You?

When mice are given DES at the time of development, the resulting offspring health problems mirror those seen in human DES Daughters and Sons.

Mice are recognized as good predictors of the human experience. So, when the children of these mice, the DES Grandchildren mice, developed problems, researchers raised a warning flag.

Scientists are now investigating whether human DES Grandchildren have been affected by a drug given to their grandmothers. As study results come in, there is growing evidence that your generation has been adversely impacted.

What We Know About DES Grandchildren

- **Delayed Menstruation Regularity** — DES Granddaughters participating in the long-running National Cancer Institute (NCI) DES Follow-up Study reported menstruation starting at about the same age as unexposed women. But it took longer for DES Granddaughters to achieve regular menstrual periods, meaning their cycles were predictable within five days.
This small study also suggests the possibility that infertility may be more frequent in DES Granddaughters, but further studies are needed.
- **Hypospadias** — A study done by The Netherlands Cancer Institute indicates that male children of DES Daughters may be at greater

risk for this birth defect than unexposed individuals. Hypospadias is a condition where the urethral opening on the penis is in the wrong place, emerging somewhere down the penis shaft instead of at the tip. In many cases hypospadias can be corrected with surgery. Of note is that other studies have failed to replicate this finding.

- **Tumor Growth** — Animal studies indicate a higher rate of tumor growth in DES Grandson and Granddaughter mice than in unexposed animals. But researchers caution that more studies are needed to prove conclusively that this finding in DES-exposed mice also occurs in humans.
- **Overall Cancer Risk** — Human studies of DES Grandchildren, at this time, find no overall increased cancer risk for DES Grandchildren.

However, research done as part of the NCI DES Follow-up Study found the number of ovarian cancers among DES Granddaughters greater than expected. This report supports further study and health monitoring of DES Grandchildren.

No increase in testicular cancer was found for DES Grandsons, nor were there any cases of vaginal/cervical clear cell adenocarcinomas (CCA) among DES Granddaughters. CCA is the cancer that DES Daughters (your mothers) should be checked for every year.

What To Tell Your Doctor

Studies of DES Grandchildren are just getting underway and some doctors may not have heard of them.

Tell your doctor of your DES exposure and that you would like to discuss it further in subsequent visits. Note your exposure on the intake form or request that your doctor do so

on your chart.

Pay attention to new DES Grandchild research results you can read in the DES Action VOICE newsletter by becoming a member.

Currently, there are no special health screenings identified for DES Grandchildren.

Discussing DES With Your Parents

When you speak with your parents about DES, you may want to share this pamphlet with them.

Visit the DES Action web site at www.desaction.org to learn more about health concerns for DES Daughters and Sons. This may be a time when you can educate your parents regarding something important in their lives.

Think carefully about when you want to bring this issue up with your parents.

Always remember that you, your parents, and your grandparents did nothing wrong when it comes to having DES as part of your health histories.

Unfortunately, drug companies heavily promoted the use of DES to doctors, even after studies were published showing that DES did not work to prevent miscarriage. We have since learned it caused problems for all who were exposed. This is why you need to be vigilant about your own health care

Are You A DES Granddaughter Or DES Grandson?

You may not be able to tell. Hopefully, your parents told you about DES being part of your family health history. If so, they deserve credit because that is not an easy discussion to have.

What might make you suspect it? If your mom mentioned having problems such as difficulty getting pregnant, miscarriages or reproductive tract cancers. Or, if there was any

family discussion about a drug given to your grandmother while she was pregnant, then you may be a DES Grandchild and should pay attention to that possibility.

As time passes, it becomes increasingly difficult to obtain medical records, so that avenue of confirmation may not be available to you.

DES ACTION USA

www.desaction.org

We are a national, non-profit consumer organization dedicated to helping DES-exposed individuals and health care professionals with important health information. We advocate for research funding and stay in touch with scientists to keep them aware of health issues experienced by the DES community.

Joining Has Its Benefits

- DES Action VOICE Newsletter – published quarterly with accurate research, legal and health information about DES that you can't get anywhere else.
- Feel good about doing something positive in support of a cause that affects you.
- Join thousands who recognize the importance of having a strong voice for the DES-exposed.
- Keep the DES tragedy from being forgotten and from being repeated with other drugs.

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Federal Judge Who's Handled Many DES Cases Calls On Courts To Be Empathetic

By Fran Howell

A large copy of the last known photograph of President Abraham Lincoln, taken just days before his assassination, hangs in the judge's conference room of the Federal Courthouse in the Eastern District of New York.

Those gathered for the 2009 Sidney Shainwald Public Interest Lecture at New York Law School (sponsored by the school and Attorney Sybil Shainwald in honor of her late husband) could easily envision the 16th president's haggard face and sad eyes, as described by The Honorable Jack B. Weinstein. He began his presentation by reminding us that Lincoln's face reflects a connection to all humanity and is the picture of empathy.

During his speech, it became clear just how empathic Judge Weinstein



Judge Jack B. Weinstein

is. He frets about inequalities in our country and what being equal really means. His first example described the situation of DES Daughters who deal with health consequences because their mothers were prescribed a drug during pregnancy.

"In what respects are people equal?" he asks. "How do we judge equality?" Weinstein wrestles with these perplexing decisions daily in his courtroom and acknowledges there are no easy answers in the real world.

Harkening back to the large Lincoln photograph, Weinstein describes the sad countenance as reflecting a connection to all humanity; the picture of empathy. Weinstein calls it a reminder to judges that those who come before them depend on both their wisdom and their empathy.

He says protection of rights has generally improved in the 60 years that he's been practicing law. "Women, minorities and the disabled now find courts

available to them in many cases." But he acknowledged that various issues, including statute of limitations laws, routinely keep courthouse doors closed to those who should be able to file suit. Especially in cases like DES exposure, Weinstein supports the removal of unreasonable procedural barriers encountered by plaintiffs seeking redress in court.

During a question and answer session, DES Action USA Board Member Cheryl Roth raised concerns about the legal rights of DES Grandchildren. Judge Weinstein immediately recognized the issue, and even broadened it out to say that DES Sons have similar concerns. His reply, "Our judicial system has come a long way but it is far from perfect. Keep trying." **DES VOICE**

Editor's Note: DES Action USA has begun discussions with pertinent individuals in the field to see what can be done to establish legal rights for DES Grandchildren.

BOOK REVIEW

New Book By DES Daughter On Oprah's Summer Reading List

what i thought i knew

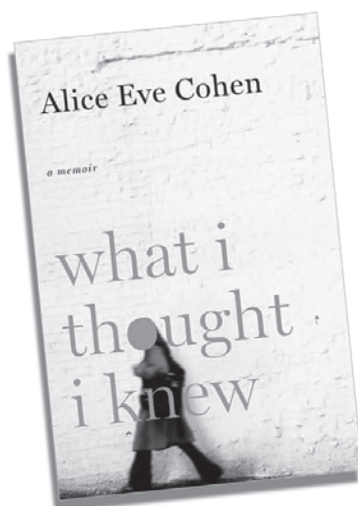
by Alice Eve Cohen,
Viking, \$24.95

Reviewed by Fran Howell

My plan was to send this book to another DES Daughter for review. But before shipping it, I read the first pages and could not put it down. The book never got mailed.

Alice Eve Cohen's story is familiar to those of us in the DES community, we who are no longer surprised by terrible mistakes in health care. But the ones made in her case were especially horrific. And another life was involved.

Cohen was told at an early age that she could not get pregnant because she was a DES Daughter with a small



and malformed uterus. So she got on with her life, adopted her daughter and was doing well at age 44, until she started feeling poorly. When doctors finally figured out what was going on,

she was already six months pregnant.

I took to carrying the book around while doing chores, hoping for a spare moment to dive in again. Written in short anecdotes, it is easy to start and stop. I found myself flipping sporadically to the back flap author photo, looking into Cohen's eyes and wondering how I would have responded had I been in her shoes.

Read from the perspective of an infertile DES Daughter, this book triggered feelings in me that I didn't know I had. Cohen takes us along for her roller coaster ride of emotions through nearly improbable twists and turns of fate — puzzling through the complexities of love, mothering and family relationships. The story has the added advantages of being well written, and true. **DES VOICE**

DES Exposure: Research Needed for the Generations

Dr. Vivian Pinn, Director of the Office for Research on Women's Health, held workshops this spring around the nation on "Moving Into the Future: New Dimensions and Strategies for Women's Health Research." We are encouraged that the consensus of these workshops was strong support for community-based research, a theme DES Action USA has been promoting for over 30 years. Our Program Director Kari Christianson presented written testimony to the California workshop on the research concerns we have:

Thank you to the National Institutes of Health, the Office of Research on Women's Health and the University of California, San Francisco for this opportunity to provide written testimony about the research concerns of almost 10 million DES-exposed people in the United States.

For over 30 years DES Action USA has been advocating for individuals who were prenatally exposed to diethylstilbestrol (DES). DES Action USA is the national, non-profit consumer organization dedicated to helping DES-exposed individuals with important health information, to informing the public and health care professionals about the health and fertility concerns related to DES, and to advocating for research about the health effects to all generations affected by exposure to DES.

Many terms that could be used to describe the DES-exposed population: the canaries in the endocrine disruptor coalmine, the silent generation of infertility and reproductive tract cancer, the forgotten medical tragedy. But these limited descriptions carry the stories of real people who have suffered a range of health concerns, many of which have been ignored or dismissed by health care providers. Without the research efforts of the National Institutes of Health this population would never have been studied at all.

It is with acknowledgement of what already has been learned from studying DES exposure that we advocate for renewed emphasis on DES research. There is still much that can be and needs to be learned about DES exposure, particularly as the research community continues to find increased risks for adverse health effects among DES Daughters and needs to assess real and potential health concerns of DES Granddaughters.

In the past few years the National Cancer Institute DES Follow-up Study found an almost two-fold increase in breast cancer risk among DES

Daughters over the age of 40, an increased incidence in uterine fibroids and paraovarian cysts, and a slightly earlier onset of menopause. These findings have been added to the small but lifelong risk for clear cell adenocarcinoma of the vagina or cervix, a higher incidence of neoplasia, structure changes of the reproductive tract, including the vagina, cervix, uterus, fallopian tubes and ovaries, which can adversely affect fertility, causing a higher risk for ectopic pregnancy, miscarriage, preterm labor and infertility.

Research on the health effects of DES Granddaughters, another generation affected by the DES given to their grandmothers, is of great need now. Recent studies have indicated there may be some concern about overall fertility based on the delayed onset of menstrual regularity. Also, there was the troubling finding of several cases of ovarian cancer within the cohort of DES Granddaughters. These preliminary findings require more research, not only for this generation of the DES population, but also for researchers and the public concerned about all epigenetic exposures to hormonally active substances.

The DES-exposed cohorts of the National Cancer Institute are the best available populations for continued research into the effects of DES, the first known endocrine disruptor, and for understanding the health effects of generational exposures. The DES-exposed population of daughters and granddaughters provides the opportunity to understand developmental biology, emerging diseases and conditions which may affect women's health differently, as well as address how research information can be and is translated to health care delivery.

Most certainly, for the DES-exposed population "Moving Into the Future" means continuing to learn from this human tragedy, which has been and still is a vital and timely research opportunity.

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Our DES Action Voices Go To Harvard

We are honored to report that a continually updated collection of *DES Action VOICE* newsletters will be housed at the Schlesinger Library of Harvard University.

The library's holdings are especially rich in the areas of women's health, feminism, and volunteer and civic efforts — such as the grassroots organizing movement from which DES Action USA grew in the 1970s.

Our newsletter has found a good home and is in good company. The papers of Attorney Sybil Shainwald and women's health activist Barbara Seaman are also housed at the Harvard library.

Pat Cody's book, *DES Voices: From Anger to Action*, along with DES Action brochures printed through the years, will be part of the collection.

DES Action VOICE, Volume 1, Number 1, was published in January 1979, and the newsletter has gone out quarterly since then. It chronicles the struggles and successes we've had through three decades of action in the areas of promoting DES research, education and health care for those exposed to DES.

The Schlesinger Library book collections number some 80,000 volumes on all aspects of women's lives, along with more than 400 periodicals and newsletters documenting both the wide variety of women's interests and the zeal with which they have been pursued. DES Action USA is honored to have our publications included. The website for the Schlesinger Library is www.radcliffe.edu/schles.

DES VOICE

