THE DES ACTION VOICE
A FOCUS ON DIETHYLSTILBESTROL
Spring 2000 • #84

Warnings on Hormone Replacement

By Pat Cody

MANY years ago, researchers and clinicians urged caution on DES daughters' use of estrogen in the form of the pill. The "DES Task Force Summary Report" from the U.S. Dept. of Health and Human Services in 1978 stated that "in view of the lack of information on long-term effects of estrogens in these women (DES daughters) the committee felt that oral contraceptives and other estrogens should be avoided." Even earlier, in 1977, a World Health Organization group on Steroid Contraception and the risk of Neoplasia concluded that "At least 70% of women exposed in utero to diethylstilbestrol have vaginal and cervical adenosis.... It is inadvisable to prescribe steroid contraceptives for women with vaginal adenosis." And, in 1983 the Dept. of Health Services in California in its publication for health care providers on DES daughters stated that "No long range studies have been published concerning the effect of oral contraceptive use on the cancer risk of DES daughters. In the absence of definitive data, some physicians prefer not to prescribe preparations containing female hormones to their DES-exposed patients, but to recommend other contraceptive methods instead."

The years have passed. Now DES daughters are approaching menopause, and being urged by their physicians to take estrogen in the form of hormone replacement treatment (HRT). They have been told that the hormones will protect them against heart disease and osteoporosis.

Recent reports on HRT are disquieting. First, as to effects on heart ailments, a study reported in March at the annual meeting of the American College of Cardiology showed, in a study of 2,762 women with heart disease, that estrogen supplements did not lower the risk of new heart attacks. Next, early in April, directors of a national study of 27,000 women on HRT notified the women that in the first two years of taking HRT they have a slight increase in heart attacks, stroke or blood clots. Significantly, this report is on healthy women who do not have heart disease.

And finally, a second report on HRT and breast cancer, published in the February 16, 2000 issue of the *Journal of the National Cancer Institute*. (In the last issue of the VOICE, Winter 2000, we reported on a study in the *Journal of the American Medical Association* (JAMA) of 26 January 2000 that discussed the risks of combined HRT drugs). In this latest article, researchers studied 1,897 postmenopausal women on HRT compared with a control group of 1,637 women. They found that HRT use was associated with a 10% higher breast cancer risk for each 5 years of use. Risk rose substantially to 24% higher for CHRT—Combined treatment where a progestin was added to estrogen for the entire monthly cycle. And the greatest risk, 38% higher, was when SEPRT was used: when progestin was only during part of the cycle as indicated by the words behind the initials, Sequential Estrogen plus Progestin Replacement Treatment. The authors write:

"These data strongly refute the notion that progestins will be protective against breast cancer development, a belief that has persisted despite the absence of any strong biologic rationale for an anti-estrogenic, anti-cancer effect of progestins on the breast. In fact, this study provides the strongest evidence to date that progestins not only do not protect the breast from the carcinogenic effects of estrogen but also increase substantially the small ERT (estrogen replacement treatment)—related increase in breast cancer risk. The biologic effects of progestins on the breast, while not extensively studied, support the observations in this study that progestins may enhance breast cancer risk."

These studies did not screen for DES exposure, so there may well have been some DES mothers in these groups. We have no way of knowing, at this time, if the risks described above will be greater for DES daughters, but the caution cited in the first part of this review should be kept in mind. ■

Update on DES Internet Listservs

by Sally Keely (aka "DESxposd")

THERE are now several DES e-mail lists that you may be interested in joining!

DAL, the DES Action Listserv, is exclusively for DES Action members. This list is primarily informational and provides a direct link between DES Action staff and our members. To subscribe, send e-mail to DAL-request@telelists.com with the command "subscribe YourFirstName YourLastName" (without the quotes) as the only thing in the body of the message. Be sure you replace "YourFirstName" and "YourLastName" with the name under which your DES Action membership is listed. You will receive a confirmation request to which you simply hit reply and send. If you have any problem, e-mail DAL-owner@telelists.com.

DES daughters should check out DES-L, the DES daughters' listsev and online support fourum at http://www.surrogacy.com/online_support/des/ To join the listserv, complete the online application and get ready to share support and information with 1000 other DES daughters!

DES sons will want to join the DES-Sons list for confidencial discussions of issues related to DES exposure in males. This list was developed in conjunction with the DES Sons Network of DES Action. To subscribe send blank em-mail to des-sons-request@egroups.com. Direst questions to des-sons-owner@egroups.com.

The DES-Family list welcomes all DES-exposed, their family, and friends. To join, e-mail listserv@sact.com with only the command "subscribe des-family" (without the quotes) in the body of the message. Charli@egroups.com can help if you have questions.

Lastly, announcing the newest DES related listserv, DES-Pregnancies. DES daughters who are pregnant, trying to conceive, or contemplating pregnancy are invited to join via the list website http://www.onelist.com/subscribe/despregnancies. You will need to register with onelist, if you aren't already. Contact ladonnakat@aol.com if you have trouble subscribing.

Now, happy chatting!

DES Action Affiliates and State Contacts

DES Action Affiliates

Each affiliate was created and nurtured by volunteers. Write to them if you want information or would like to volunteer.

DES Action USA National Office
1615 Broadway, Suite 510
Oakland, CA 94612
desact@well.com

DES Sons Network
104 Sleepy Hollow Place
Cherry Hill, NJ 08003

DES Third Generation Network
Box 21
Mahwah, NJ 07430
Des3gen@aol.com

DES Action San Jose *(California)*
5835 Terrazo Court
San Jose, CA 95123

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12445 Drake St., NW
Coon Rapids, MN 55448

DES Action Pennsylvania
Box 398
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DES Action Washington
719 15th Avenue, East
Seattle, WA 98112

State Contacts

State contacts participate in national projects organized by DES Action. Contact the national office if you would like to find out about our national projects.

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Los Angeles, CA
San Diego, CA
Grand Rapids, MI
New Jersey
New Mexico
Ohio
Oregon
Texas

DES Action International

Australia
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Notes from Nora

I was honored to be one of the guest speakers at an event celebrating the 25th Anniversary of the National Women's Health Network. The theme of the evening was "Countering Corporate Control of Women's Health." Here, reprinted, is the speech I delivered at that event, held on March 9, 2000 in Berkeley, CA.

WAS there DES in your dinner last night?

In February the Wall Street Journal printed a story with the headline "U.S Launches Probe After Switzerland Finds Illegal Hormone in American Beef."

That hormone was DES, banned for use in cattle feed in 1980, nine years after the link between DES and cancer of the vagina and cervix was found in young women exposed in utero to this carcinogenic hormone drug. It was banned in cattle after the FDA determined that they could not find a level of DES that was safe for human consumption.

1980. That's a long time ago. We are all wondering: where did the cattle producers get it, after all this time? Is it still being produced by someone, or has it been stockpiled for over twenty years?

The USDA stopped testing for DES in beef back in 1991, after not finding it for several years. Since this March news report, and protests from DES Action and other consumer groups, they recently announced that they would once again begin spot checks in stockyards.

Some people, particularly some doctors, prefer to think of DES as an old story with little relevance today. Many others confuse it with thalidomide or simply don't know what it is. It's such a pleasure to speak to a group of people who I can pretty safely assume know about DES. This becomes more and more difficult to find as time goes by. And just when we start to think of DES as a thing of the past, something like the tainted beef story comes along to remind us of the power of the profit motive, and the incredible persistence of drugs that can make money.

"It's relentless, and it's hard to resist the drumbeat. Can you imagine if DES had been marketed directly to consumers? We might be talking about 50 million."

We live in what my friend Lisa Summers calls a "pharmaco-optimistic society." The onslaught of pharmaceuticals is more overwhelming than ever before, thanks to the new era of direct-to-consumer-advertising. Every day now we can see ads for Meridia, Claritin, Relenza, Nolvadex. Have you noticed that all of the people in these ads are women? Sales are up. "Ask your doctor," and people do. Women are the medical consumers in this country, and we are the targets.

As the huge baby boom group moves through menopause, we are an enormous market for hormone drugs. Every stage of a woman's reproductive life offers opportunities for hormone use. When you start menstruating, you can go on the pill. From the 1940s through the early 1970s—over thirty years—5 million pregnant American women were given DES to not only prevent miscarriages but to make their babies bigger and stronger. As women age and enter menopause, they can take more hormones! Recent research tells us, however, that if you do take menopausal hormones you'd better be prepared to choose between your breasts and your uterus. But still, we're told, women should not be denied the benefits of those hormones. They're essential for your health.

It's relentless, and it's hard to resist the drumbeat. Can you imagine if DES had been marketed directly to consumers? We might be talking about 50 million DES mothers, instead of 5 million. One ad, for DESPlex, recommended "for routine prophylaxis for all pregnancies" and promising better babies, was only seen by doctors in a medical journal.

It's a very appealing image. It's easy to imagine the commercials. The anxious young couple, hearing the bad news in the doctor's office. "With your pregnancy history, I'm very concerned about a miscarriage. But now there's a new treatment that can help you." Cut to scenes of the joyous couple, holding the beautiful baby post-partum. "Ask your doctor about DES. Side effects may include nausea, sleeplessness, dry mouth, irritability and constipation." Of course there would have been no

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mention of cancer, malformed reproductive organs and infertility of the offspring, since these side effects didn't turn up for many years. What had turned up, however, was cancer in laboratory animals. What had turned up as early as 1953 was that DES was completely ineffective for its stated purpose.

Kind of like Relenza, apparently. Have the drugs that are presently being marketed on television been thoroughly tested? Do we know everything we need to know about their long-term side effects? We should be deeply troubled when we hear reports like the recent stories about the diabetes drug Rezulin, currently under investigation by the FDA. Even though the FDA issued repeated warnings to doctors to closely monitor patients taking the drug for liver damage, the FDA reports that less than 3% of people taking Rezulin were in fact monitored properly.

Ironically, women exposed to DES are more likely than their peers to take pharmaceuticals, due to their higher rates of infertility and pregnancy problems. Just today the CBS morning show featured a report about a DES daughter with a thin uterine lining who became pregnant with the help of Viagra. Apparently Viagra causes the blood vessels in the uterine wall to dilate, and this carries estrogen from the ovary to the uterine lining. Like DES, however, Viagra can harm a fetus and must be stopped before pregnancies. The ironies abound.

DES Action is currently involved in a campaign to counter ads for Tamoxifen, also known as Nolvadex. We are working with the National Women's Health Network, Breast Cancer Action, and other groups to give women the full story about this drug.

Ads for tamoxifen, which is touted as a breast cancer preventive, play up the benefits of this drug for preventing breast cancer while downplaying the fact that it increases the risk for endometrial cancer, carries other serious health risks, and has very limited benefit for a small group of women. It would be interesting to see someone on an ad for tamoxifen read from the product insert, which I have here. I chose at random the subheading "impairment of fertility."

It reads: "Fertility in female rats was decreased.... There was a decreased number of implantations, and all fetuses were found dead. Following administration to rats...there were increased numbers of fetal deaths. Administration of .125 mg. to rabbits during pregnancy resulted in abortion or premature delivery. Fetal deaths occurred...." Well, you get the idea. Now, if you are a woman with metastatic breast cancer taking tamoxifen to prevent recurrence, you may accept a higher risk. But this drug is being marketed to healthy women with no history of breast cancer, although with a higher risk for it.

Our tamoxifen campaign is part of a longer term goal to promote the precautionary principle of public health, and to educate people about real prevention. In these goals we find ourselves at odds with the pharmaceutical companies, who have nothing to gain, and in fact much to lose, from teaching people to be cautious about their drug intake and about prevention. The latter involves not only the lifestyle changes we can all make to be healthier, but as communities reducing our exposures to chemicals, pesticides, and harmful drugs. This is a political question and one with powerful adversaries.

Often we find ourselves fighting the government's health priorities as well, as our leading cancer experts focus on finding that magic curative pill rather than looking at what environmental exposures might be, for example, dramatically increasing the rates of childhood cancer and asthma.

I have found myself to be an unpopular guest at dinner parties when I get started on this, unless the dinner parties are attended by people like Theo Colborn or members of Greenpeace. Even progressive-minded people don't like to dwell on such negative issues. We feel powerless when confronted with such major challenges as environmental destruction and the vast array of toxic chemicals that surround us. Yet I take heart from the inspiring examples of women like Cindy Pearson, Adriane Fugh-Berman, Judy Norsigian, Barbara Brenner, and my mother Pat Cody. They have shown me what determined individuals can accomplish. They have all inspired others to join with them in a still-strong women's health movement. Our movement, partnering with social justice and environmental organizations, can move mountains, if we have to do it one stone at a time. I encourage you to join the National Women's Health Network, pick up your stone, and help us move the mountains. Thank you. ■

Letters to the Editor

Dear Editor:
Thank you for the informative Web site. I'm printing it all and taking it to my doctor. He can stand to be a little more educated. I thank you.

Patti

Dear Editor:
I'm writing you from England. I discovered I was DES exposed, or should I say the hospital discovered I was DES exposed about 13 years ago, although I only found out about 7 years ago. My medical records, when I finally got my hands on them, stated their finding together with the words "THE PATIENT HAS NOT BEEN TOLD". They try to hide everything over here....

Cheryl

Dear Editor:
In response to some daughters belief about being thankful they're here—I too am very thankful I am here, but I'm not here because DES worked. I am the sole survivor of my parents' 9 pregnancies, 6 of which my mother took DES. Our family is a quintessential example of DES NOT working. I'm certain there are others who have similar family situations. The introduction of DES and the fanfare that surrounded it was based on non-empirical research of a husband and wife team, Olive and George Smith. They did not use scientific testing. Stilbestrol "therapy" was the Smiths' report of their measuring of progesterone levels in the urine of women who had miscarried which they found to be low. The Smiths postulated that Stilbestrol or any synthetic estrogen therapy for pregnant women would increase their progesterone levels....

By 1953 there were 14 reports from independent prominent medical centers that Stilbestrol was ineffective in pregnancy. The tragic part of the DES story is that the drug companies who manufactured and sold DES knew all of this, but failed to inform the FDA, thus there was a significant number of exposed individuals born after 1953. Please don't believe you are here because of DES, if anything, believe you are here by some miracle!

Jill

"My medical records, when I finally got my hands on them, stated their finding together with the words 'THE PATIENT HAS NOT BEEN TOLD'".

Dear Editor:
I want to share something which might help other daughters get their doctors to hear them about the new Pap smear. I was researching and came across the ASCCP (American Society of Colposcopy and Cervical Pathology) practice guidelines on Pap Smears, which actually gives specific guidelines for DES daughters' vaginal Paps. I gave a copy to the pathologist who will now use it as a guideline. In case you haven't seen it, it is available on the web via:
www.guideline.gov Go to "search" and type in: pap smear. Several articles will pop up—go to the one titled "Management Issues Related to Quality of Smear." It has ASCCP recommendations for optimal pap collection. Middle of page 4 in the paragraph on vaginal pap smear, it has a couple of sentences on DES exposed and 4 quad pap (although they don't exactly call it that). They write:

"For diethylstilbestrol-exposed women, a sample from each lateral vaginal wall should be laid side-by-side on one slide and immediately fixed. The speculum should then be rotated, and the procedure repeated on the anterior and posterior vaginal walls."

The rest of the summary gives good advice on pap technique and also gives the medical journal article source for these guidelines.,

So, if you are having trouble getting your doc to hear you on the need for this and perhaps have no option to change providers, then try taking in the entire summary as "evidence." As some docs cringe when handed a pile of papers, it might be better to circle and point to that one appropriate paragraph on page 4 when handing it over.

This is a specific U.S. government sanctioned guideline now—any daughter can download this, circle that paragraph, and hand it to their doc if they ain't being heard. Worked for me with some of the more stubborn docs.

Sandra

Dear Editor:
I want to thank all of you who put the idea into my head to attempt a lawsuit. Why on earth I had never even thought of it before, eludes me.

I think when we find out about our DES exposure, we are

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Report on Pregnancy Outcomes

AT our Symposium in October, Candy Tedeschi, Nurse Practitioner and Nurse Colposcopist, spoke on early findings from the study on DES mothers, daughters and sons. Candy is familiar to many of you in the New York area for the years of medical care she has provided to thousands of DES daughters. Candy's involvement in the DES issue extends far beyond her professional life and she currently serves on DES Action's board of directors. Her full report will be in the transcript we are publishing from the Symposium. Here we excerpt her discussion on pregnancy outcomes for DES daughters.

"The last study is of pregnancy outcomes. Researchers looked at two cohorts, the DESAD Project and the Dieckmann group. They looked at over 3300 exposed and about a thousand unexposed. They looked first at the general health history and then at first pregnancy outcomes, the age of that outcome, their pre-term births, terminations as abortions, miscarriages, ectopic pregnancies, still births and neonatal deaths. When they looked just in general at menarche, that's the age when a woman first starts getting her period, there were no differences between any of the groups. Age at first pregnancy—no difference. There were more smokers in the unexposed group as opposed to the exposed.

When they looked at full term, over 84% of the unexposed had a full term baby, only 64% of the DES daughters had a full term baby. The DES daughters overall had fewer full term live births, more premature births, more miscarriages, more ectopics. This is all information we've already known, but at least is another confirmation of what we've known and it's another reason why we need to have proper prenatal care for these women. I looked at, this is the record review, the physicians' referral and the walk-ins and if you look at full term babies, this is the number in each group. 85% of the unexposed had full term babies as opposed to between 52 to 64% of DES daughters had full term babies. Premature—Only 4% of the non-exposed or control group had premature babies all the way up to 18% for the DES- exposed. Stillbirths—.3% (3/10ths of one percent) of the controls had a stillbirth. We averaged a little over 1% (over 3 times the rate that the unexposed had) in the DES exposed. Miscarriage—about 10% of the controls had miscarriages and you can see in the DES group that about a little over 20% had miscarriages. Ectopic—in the control group .8 (8/10th of one percent), where between 4 and 8% of the DES exposed had ectopic pregnancies. It goes along with those infertility rates too.

We talked about different hormonal problems for the miscarriages or even tubal problems for the ectopics. So again this is going over it again, more ectopics (somewhere between 7 and 11%) as opposed to 1.9% for the control group. Neonatal deaths—a little less than 2% as opposed to .3 (3/10th of one percent) in the controls. And they associate the neonatal deaths with an increased risk of premature deliveries. *

They looked at cervical incompetence to see if that would increase the risk of second trimester miscarriages and they found that, yes, there is an increased risk. DES daughters do not have the same type of cervical incompetence that we think of as most doctors think of, where the cervix is dilating. With many DES daughters, their cervix effaces, that is, it thins out sooner. What you need is early diagnosis, so these women need ultra sound surveillance throughout the pregnancy. Some doctors will do a combination of feeling the cervix and doing ultra sounds to actually measure how thick the cervix is. Is it thinning out too soon? They are recommending cerclage only in those who are demonstrating change and there should be no such thing as a routine cerclage What is cerclage? Cerclage is a stitch they put into the cervix that ties the cervix shut. Cerclage is not without its own risk of infection and miscarriage, plus the risk of the anesthesia and there are doctors, I know several in this city, NY City, who put them in as routine for every DES daughter. Cerclages are never routine, they should be used only in women who absolutely need them and there are many doctors who use bedrest instead and it works just as well.

With the effect of upper genital tract problems, in other words the T-shaped uteruses—we have always associated them with a poor pregnancy outcome,

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Infertility Insurance Bills in Congress

By Sally Keely

INFERTILITY diagnosis and treatment should be covered by all insurance companies. My infertility is caused by both a disease, PCOS, and of course DES exposure. However, my insurance company (I work for Washington state in the community college system) does not pay for ANY infertility diagnosis or treatment. So, I'm passing along the following information about the FAITH 2000 infertility coverage bill before the Senate, in the hope that you will take a moment to support it.

U.S. Senator Robert G. Torricelli (D-NJ) introduced S.2160 in March. This bill is called the Fair Access to Infertility Treatment and Hope Act of 2000 (FAITH) and it requires all health plans to cover infertility diagnosis and treatments. For ART (Assisted Reproductive Technology) procedures such as IVF, it requires coverage of 4 completed embryo transfers, and if a live birth results from one of those transfers, at least two additional transfers must be covered. It also requires coverage of drug therapy and insemination.

This bill joins the two insurance bills in the House: HR 2706, introduced by Rep. Anthony Weiner, requires all health plans to cover these services, and HR 2774, introduced by Rep. Marty Meehan, requires such coverage in federal employees' health plans.

It is very important that Senators hear from their constituents about the need for infertility insurance coverage. Also, we must continue to contact Representatives about the House bills. Contact your two members of the Senate and your one Representative and ask them to co-sponsor the bills listed above. To find contact information for Senators go to http://www.senate.gov and for Representatives go to http://www.house.gov. You can also reach all members of Congress through the Capitol switchboard at 202-224-3121 or by writing to them (which may carry more weight than e-mail) at:

Senator (name)
United States Senate
Washington DC 20510

Representative (name)
United States House of Representatives
Washington DC 20515

The RESOLVE web site has a sample letter posted at http://www.resolve.org/advocacy.htm that can be used, or write your own. I find personal experiences are very impressive. ■

LETTER TO THE EDITOR from page 5...
so shocked and suddenly confronted with tests, doctors, and our DES problems, and their effects on our partners that we just don't even think about retribution.

I look back, as yesterday was the one year anniversary of my hiring my lawyer. My lawyer flew to meet my mother today, for her deposition at Lilly's law firm.

What a turnaround my parents have made. One year ago, my mother wanted nothing to do with this, she was very discouraging and my father wanted nothing to do with hearing about these intimate female details.

My lawyer and his team have been WONDERFUL, and I mean really wonderful with my parents. Dad is all excited about this and will even say the word "uterus" to me on the phone (sounds like nothing, but this is a major deal) and my mother has remembered amazing details and has pinpointed and positively identified Lilly as the maker of the DES. She is so proud to finally after all these years of guilty feelings, and now watching my futile attempts at fertility treatments, to be able to do something for me.

The law firm call my parents regularly and even sent them transcripts (is this the correct word?) of previous depositions and DES trial proceedings. I am very impressed and know there is still a long wait ahead. If any of you are considering a lawsuit, please, please do it. It will in no way make up for what we have been through, but it will make you feel a heck of a lot better.

Your DES sister

PREGNANCY OUTCOMES from page 6...
but when they looked overall, they couldn't find any one particular item that would cause a poor outcome, so they are not sure exactly what the relationship is. I've got two slides. Early sonograms are very important, as soon as a DES daughter feels she is pregnant, she should get an early sonogram about two weeks after a missed period, to make sure that the pregnancy is in the uterus and not in the tube. Ectopic pregnancies are life threatening. If you cannot confirm the pregnancy in the uterus, you get serum blood test every two days until you can confirm it, then you do digital exams and ultra sounds every one to two weeks from the second tri-mester on, every week in the third tri-mester to monitor for cervical effacement and dilatation. Cerclage should only be considered with early effacement or dilatation or if the woman has had a prior second tri-mester loss I know I've gone through everything really quickly and I'd be happy to go over any of this individually with you. There were just so many studies to go through and I could only give you the high lights .

To look at infertility they used the Dieckmann group, and the DESAD project and they asked, "Do DES women have a higher risk of infertility for either hormonal or ovulatory reasons?" Also, do they have a higher risk due to the structural abnormalities, T-shaped uterus, ridges, hoods or the fallopian tubes? Many of the women gave more than one reason why they had infertility. Now I am going to show you two graphs. These were all the women, the number of exposed vs. unexposed, and who listed the different reasons why they had infertility. And when we look at them overall, statistically, the uterine problems, the T-shape uterus, the researchers believe that hormonal ovulatory problems seem to hold out as being the biggest causes of infertility."

* *The statistics in our report in our Fall issue 82 were transcribed incorrectly. These are the correct figures.* ■

22 YEARS OF

DES ACTION

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