

DES—exposed Consumers Outraged to Find Illegal DES in American Beef

ON February 2, the Wall Street Journal reported that authorities in Switzerland had detected DES in two shipments of American beef, “triggering a major U.S. investigation to pinpoint the source of the banned carcinogen and to determine how much domestic and export beef may have been contaminated.”

The Swiss government notified the Clinton administration last July that DES, which is illegal in the U.S. and Switzerland, had been found in two samples of supposedly hormone-free U.S. beef, and that it had barred two US companies from exporting to Switzerland. One of the companies is Farmland National Beef Packing Co. of Liberal, Kansas, the fourth-largest meatpacker in the U.S.

Cattle and sheep producers relied heavily on DES as a growth stimulant until 1979, when the FDA banned its use in food-producing animals, but not pets. The FDA also concluded there was no way of determining what levels of exposure to DES might be safe.

“The Swiss government notified the Clinton administration last July that DES, which is illegal in the U.S. and Switzerland, had been found in two samples of supposedly hormone-free U.S. beef.”

In response to this report, DES Action issued the following press release:

We are dismayed but not surprised to learn that DES (diethylstilbestrol) has been found in beef exported from the U.S. to Switzerland. In spite of the years of horrors wrought via this carcinogenic substance, DES apparently remains a popular toxic tool for some cattle farmers.

“This is just incredible,” said Pat Cody, who took DES while pregnant with her daughter Martha. “To think that this drug which has harmed my daughter and so many others could now be hurting my grandchildren when they eat a hamburger.”

DES use in humans persisted far beyond the dictates of both medical science and common sense. Even though a reliable, well-done study in 1953 showed that DES was ineffective for its prescribed purpose, i.e. preventing miscarriages, pharmaceutical companies continued to make it and doctors prescribed it until 1971. Its use in cattle was finally banned in 1980 but this has not

deterred some unscrupulous cattle producers from once again exposing the public to this toxic substance. Ironically, it took a foreign country—the more cautious Switzerland—to uncover this use in the United States.

We call on the FDA and the USDA to move swiftly to not only sanction the offenders but to also enact more stringent controls to protect the public. We are alarmed that consumers are only learning about this now, when the tainted beef was discovered in July, 1999 (ironically, the same time that the National Institutes of Health convened a DES Research Conference to discuss the health effects caused by exposure to DES). We wonder if McDonald’s, Burger King, and other major burger outlets are taking steps to protect their customers from DES.

Given the poor state of beef inspection in this country, there is no way of knowing the extent of exposure to DES for American and international consumers, particularly since the USDA has not tested beef for DES since 1991. However, the fact that the source of the DES-contaminated beef was the fourth-largest meatpacker in the U.S. is cause for great concern. Clearly, the USDA must immediately resume and expand testing for DES, and do whatever is necessary to rid our food supply of this deadly carcinogen.

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Each group was created and nurtured by volunteers. Write them if you want information on their activities or can volunteer.

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Compensation Fund in the Netherlands

TWO separate settlements, totaling 76 million guilders (\$36 million), have been made in law suits against the drug companies who distributed DES in the Netherlands. Physicians in the Netherlands continued to prescribe DES for several years after the 1971 report in the U.S. on the link between DES and clear-cell cancer.

It took DES Action the Netherlands years of negotiations with the drug companies and their insurance companies to reach these settlements.

The first settlement is for six cancer daughters, who filed the original law suit in 1986.

The second settlement will be for a fund for other daughters with clear-cell as well as daughters with non-cancer injuries. Compensation will be paid according to the category of injury, with infertility at the top of the list. A fixed sum will be paid for each category, but our Netherlands group tells us that the sums are small compared with the compensation won by U.S. daughters.

Though the Netherlands is part of the European Economic Union, the Dutch DES group does not think this victory will make a difference for DES daughters in other countries, or have influence on the French law suit which started many years ago and unfortunately is still going on. ■

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Notes from Nora

PLANNING for the National DES Education Program is moving forward under the direction of the Steering Committee assembled by the Centers for Disease Control and Prevention (CDC), the public health agency responsible for carrying out this program. This Committee includes representatives from DES Action, the DES Cancer Network, the DES Sons Network, and the National Women's Health Network as well as from various health care provider communities including nurse practitioners, nurse-midwives, ob/gyns, and others.

In between ice storms in Atlanta, the committee met at the end of January to discuss our progress to date and make recommendations for the future. Keeping in mind that we always have budgetary limitations, we worked hard to come to consensus on the most important targets for our campaign and the best ways to reach them. There were discussions about how to encourage more DES sons to find out about their DES exposure, and how to reach their health care providers with current informa-

tion. We also reviewed evaluations of the previously funded pilot education projects so that we can understand what did and did not work.

One of the key components of the National DES Education Program will be to develop sustainable programs that can endure over time, rather than short term campaigns that are over and forgotten quickly.

"We will be asking our members for help in nominating individuals who might serve as DES champions."

Wherever possible, this will mean embedding DES education into ongoing institutions, such as medical schools, hospitals, nursing schools, etc. and working with local health care providers and others who can serve as "champions" of DES education. We will be asking our members for help in nominating individuals who might serve as DES champions and for assistance in

implementing other elements of the program.

The next step in the National DES Education Program will be to send our ideas and recommendations to a contractor, who will design the actual campaign. Their job is to answer questions such as "how can we convince ob/gyns to learn the latest information about DES and use that information in their practices?" and "how can we work with nurse-midwives to integrate DES education and information into their care?" They will also help to determine the media messages and channels that will have the most success in reaching members of the public who are DES-exposed. Their proposal is due in April, and will be discussed at our next Steering Committee meeting. At that time we will also receive a budget, and present the plan and budget to the National Cancer Institute—the agency responsible for funding the Program. We will need your help in convincing the National Cancer Institute to fund this essential Program. Keep an eye on your mailbox for more details about how you can help in this campaign. ■

DES Action Tribute Program

We'd like to offer a great idea for that person who has everything: the DES Action Tribute Program. Our Tribute Program is a way for you to make your contribution in someone's honor or memory. Holiday gifts, birthdays, anniversaries or memorial remembrances—all are appropriate occasions for a Tribute gift.

When you send your Tribute gift to DES Action, simply enclose a note indicating in whose honor and for what occasion the gift is given. Make sure to include the honoree's name and address as well as your own. We send an acknowledgment letter to you and to the honoree. The amount of the gift is not mentioned. ■

Reports from July Workshop

THE DES Workshop sponsored by the National Institutes of Health last July included a "poster session" where researchers could display their recent work. These summaries are often of articles that will be published in medical journals. Two of these reports are of special interest to us.

"Increased tumor prevalence in DES-lineage mice" by Retha Newbold et al from the National Institute of Environmental Health Sciences. This is a companion study to the one about

DES "granddaughter" mice published in the journal *Carcinogenesis* in September 1998 and covered in VOICE 78 (Fall 1998). Now Ms Newbold has concluded her study of the "grandsons" of DES daughter mice. It shows that these male mice also develop reproductive tract tumors, including rete testis tumor (which is very rare in both mice and humans.) Fertility of these mice was not impaired. The abstract concluded:

"Using this animal model, we can

now systematically analyze and detect changes caused by DES, which will enable us to compare similarities and differences between mice and humans. The ability to detect these genetic/epigenetic changes may represent an important advancement in future cancer therapy and prevention. Furthermore, this mouse model permits us to reach across species and learn more about mechanisms involved in cancer, in particular, the factors underlying the genetic predisposition to cancer."

The second poster abstract, by R.H. Kaufman et al, was on "Pregnancy outcome in women exposed to diethylstilbestrol in utero." Their survey covered a large number of DES daughters and of unexposed women in their age and social group. The DES group had a lower rate of full term live birth, and a higher rate of premature delivery, still birth, miscarriage and ectopic pregnancy.

Pointing out that this study is based on the largest number with documented DES exposure, the authors wrote that as these women are now on average 45 years old, this may be the last study of their reproductive experience. However, they add,

"there are still many DES-exposed women within the reproductive age range. Therefore, it is important for the obstetrician-gynecologist to be aware of the possible consequences of in utero DES exposure on pregnancy outcome, so that appropriate prenatal care is given."

Editor's note: These two reports are abstracts. The complete articles, with percentages given for tumor risks for male 'grandson' mice, or third generation, and for pregnancy problems for daughters, will be reviewed in the VOICE as soon as they appear in medical journals. ■

Letters to the Editor

Dear Editor,

I had my one-month follow-up appointment today with my gyn oncologist, and went in armed with the last two DES Action newsletters, pages I had printed from various DES related sites on the web, and e-mails of other DES daughters' experiences following cone biopsies and LEEP procedures. My doctor listened to my questions, read the materials presented, and generally seemed genuinely interested in the DES info that he had not been aware of. Thanks again for all your help. I feel so much stronger for having this resource of information available to me.

Daughter in Michigan

Dear Editor,

I was just recently diagnosed with Hashimoto's thyroiditis. At the time I wondered if it was at all related to my being a DES

daughter. Well I opened up today's issue of the DES Action VOICE and read that DES exposed individuals are at a five times greater risk of developing this disease. What timing! I have only been subscribing for a year but I don't feel I will ever be able to let my subscription go. Your newsletter is an essential resource and I am so thankful that I subscribed!

Melissa Rogers

Dear Editor,

I would like to suggest that any individual who is experiencing perimenopause-like symptoms to please have their thyroid checked. Autoimmune problems and thyroid problems quite often go hand in hand. I thought I was perimenopausal for a year before my hyperthyroidism was caught through routine blood work...hopefully, this letter might spare another from suffering for a year with those symptoms without proper care.

Reader in Georgia

Hot Flash! Healthy Ways to Turn Down the Heat

Reviewed by Molly B. Spira

"BIOCHEMICAL, metabolic and vascular mechanism in menopausal hot flashes," R. Freedman, *Fertility & Sterility*, Aug. 1998.

"Reduced thermoregulatory null zone in postmenopausal women with hot flashes," R. Freedman and Willane Krell, *Am. J. of Ob/Gyn* July 1999.

"Behavioral treatment of menopausal hot flashes; evaluation by ambulatory monitoring," R. Freedman and Suzanne Woodward, *Am. J. of Ob/Gyn*, Aug. 1992.

"a2-Adrenergic mechanism in menopausal hot flushes," R. Freedman et al, *Obstetrics & Gynecology*, Oct. 1990.

In a series of studies, scientists are learning that women who are post-menopausal, not on estrogen therapy, and yet are symptomatic and experience hot flashes, may have the ability to control their hot flashes by controlling their core body temperature and respiration rates. Hot flashes are not controlled by a woman's mental or physical well-being; rather, those are stressors that may contribute to the problem. The findings suggest that estrogen may also not play as significant a part in whether or not a woman experiences hot flashes, as many women who are estrogen-deficient are without symptoms.

Dr. Freedman and his colleagues found that women who were symptomatic displayed a much smaller temperature "null zone" between their sweating threshold and shivering threshold

body temperatures than women who had no symptoms. Core body temperatures increased significantly before the hot flash in symptomatic women, rather than from any metabolic or peripheral vaso-constriction influence. This would suggest that food intake may also not be directly related to the start of the flash, merely that it may contribute to the duration or intensity of the heat.

Studies indicate that temperature variances are more directly related to an increase in MHPG—a metabolite of brain norepinephrine—directly related to the function of the hypothalamus and central sympathetic nervous system. Clonidine, an a2-adrenergic agonist "has been shown to ameliorate hot flushes and decrease central noradrenergic activity, thus precipitating hot flashes. However, additional research is needed to determine "the precise physiologic role of the adrenoceptors in hot flashes and their mechanisms of alteration."

So how can we use this information to our benefit? One study determined how women can reduce the incidence of hot flashes, especially those who cannot or will not tolerate estrogens. Dr. Freedman found that by controlling respiration, by pacing and relaxation techniques, women could reduce the incidence of hot flashes by a full 50%. Deep breathing exercises, meditation, and visualization are all techniques that aid in the reduction of hot flashes.

The obvious cooling techniques: wearing clothing that breathes rather than constricts, and in layers so that you can easily take off and put back on when your temperature changes; drinking plenty of cool water; lowering the thermostat in your home not only at night (less than 65) but during the day as well (less than 70) are all easy, non-medicinal ways of curbing your body's thermostat and keeping it cool.

In addition, exercise—another pacing, respiration technique—while offhand may appear to increase temperatures, actually helps the body regulate more efficiently, cool down faster, and tolerate and recover more easily from temperature extremes.

Herbal remedies, which many women are turning to, are not yet fully studied. Many women are just as uncomfortable with herbal remedies as they are with estrogen. Black cohosh, currently one of the more popular over-the-counter herbal remedies, is now being tested at New York Presbyterian Hospital in a well-designed study. Prescription drugs are also available to women who suffer without relief. Clonidine (Catapres) cuts hot flashes by 50%, but it may significantly lower blood pressure and cause drowsiness and dizziness.

Hopefully, future studies will address the long term effects of these and other medications so that women who do not find relief from home remedies can make more informed and safe choices. ■

Risks of Combined HRT Drugs

Reviewed by Pat Cody

"Menopausal estrogen and estrogen-progestin replacement therapy and breast cancer risk," Schairer et al, *J. of American Medical Assn.*, 26 Jan 2000.

THERE is a good health reason to add progesterone to hormone replacement treatment (HRT) for women with a uterus, since it decreases the risk of uterine cancer, and in one Swedish study was shown to lower the risk for ovarian cancer. But there are many variables, and one of these is described in a new report.

Does (HRT) in the post-menopause, using the estrogen-progestin formula, increase the risk for breast cancer beyond the

known risks of HRT using only estrogen? This is the question studied by researchers at the National Cancer Institute. 29 screening centers in the U.S., enrolling a total of 46,355 post-menopausal women, participated in this work. There probably were DES mothers in this group, but this variable was not considered. The average age at the start of the follow-up was 58. Of these thousands of women, 2,082 cases of breast cancer were identified.

Their use of HRT in the four years before diagnosis showed that for each year of estrogen-only use, relative risk for breast cancer increased by 1%. However, the relative risk of breast cancer increased by 8% with the estrogen-progestin formula. They

also found that a body-mass index (BMI) of 24.4 or less increased the relative risk with each year of use, greater than the risks for the group as a whole.

Accordingly, heavier women had no increased risks, but slim women had increases in relative risks for each year of 3% for estrogen only and 12% for the estrogen-progestin combination. This relationship to weight is a puzzle and leads the authors of the study to conclude their report with:

"Our results, as well as those of others, suggest that in weighing the risks and benefits of menopausal HRT, it is important to consider the type of hormone regimen as well as individual characteristics of the woman, such as body mass index." ■

News

Join DES Action's New Online Listserv

All members with e-mail access are invited to join DAL, DES Action's new online network, or "listserv." To subscribe, send e-mail to DALrequest6:35:34@elists.com. In the body of the message write only the command "subscribe YourFirstName YourLastName" without the quotation marks. Please use the first and last name under which your DES Action membership is listed. When you receive a confirmation request, simply hit reply and send.

Internet Resources

Online Support Group for DES Daughters TASC, The American Surrogacy Center, hosts DES-L,

an online support group for DES daughters. The purpose of this listserv is to provide support and exchange information with other DES daughters (currently over 200 members) via the internet. Besides communicating through e-mail, DES-L offers an online bulletin board, live chat sessions, and virtual seminars (at which professionals such as physicians, attorneys, psychologists, and researchers are available to discuss your questions and concerns).

DES-L's webpage at http://www.surrogacy.com/online_support/des/ has DES articles, links to other DES websites, and an application to join the listserv. Hope to "see" you there.

DES newsgroup

There is also a DES newsgroup — check to see if your server carries it. It is called alt.support.des and it is a newsgroup for DES exposed daughters, sons, and moms. The purpose of this group is to exchange information, provide support, and post DES related announcements.

DES Action website and e-mail

Don't forget that DES Action has a website at <http://www.desaction.org>, and our e-mail address is desact@mail.well.com.

Hope to see you on the internet!

The DES Third Generation Network Questionnaire

PLEASE answer these questions (even if you have been part of our network in the past) and mail to The DES Third Generation Network, P.O. Box 21, Mahwah NJ 07430.

This information will be kept confidential and used only by members of the DES Third Generation Network.

Section I

Information about You, the DES daughter or son.

1. Your name _____
address _____
city _____ zip _____
e-mail _____
phone number _____

2. Your birth year and any information about the DES your mother took when she was pregnant with you (*for example, if you know the timing and duration of DES use*)

3. Any chronic health problems you have.

Section II

Your (or your wife's) pregnancies.

1. Obstetrical history (*infertility, cervical incompetence, uterine anomalies, miscarriage, ectopic pregnancies, etc.*)

2. Pregnancies (*include any relevant medications, technologies, as well as any problems*)

3. Pregnancy outcomes: your children: *include year of birth and length of pregnancy*

Section III

Your children, the DES Third Generation

1. Any chronic health problems your children have:

2. Any disabilities your children have:

3. Have any of your daughters been examined by a gynecologist yet? If so, list age at visit and any pertinent findings.

Have any of your sons been examined by a urologist yet? If so, list age at visit and any pertinent findings.

4. Any other concerns about your children (*use extra paper as needed*)

Our Third Generation

■
ARE you a DES daughter or son with biological children?

We are. We are concerned with our children's day-to-day life, as well as any future health problems they may face because of our exposure to DES.

The DES Third Generation Network exists to provide support and share information about our children. For example, some of our children have long-lasting health effects due to prematurity. Many of our children are fine, and we hope they continue to have no health problems.

The DES Third Generation Network is pleased to see that the scientific community is investigating the possible effects

of DES on the third generation. Retha Newbold, M.S., Head of the Developmental Endocrinology Section of the Laboratory of Toxicology at the National Institute of Environmental Health Sciences, presented results of her research at both the National Institute of Health DES Conference in July and also at the DES Symposium in October.

One subject of interest that Retha investigated is third generation effects in mice. Retha found no fertility problems in daughters of DES daughter mice, but did find that some of these third generation mice had tumors.

While we are concerned about what these findings may mean for our children, we are glad that

this subject is being investigated.

Can you help us gather more information? We would like to update our list of DES daughters and sons with biological children. As our children grow up, we want to be aware of any potential problems which might be linked to past DES exposure. We need to continue gathering our information. We can work together with the scientific community to further our understanding of the impact of DES on the third generation.

Even if you are part of our network already, please answer our questionnaire, and send it back to us. Thank you.

Bonnie Federman
Elizabeth Wandelmaier ■

PLEASE fill out and return
questionnaire on page 7.
Your Voice matters!

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