THE DES ACTION VOICE

A FOCUS ON DIETHYLSTILBESTROL

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DES Increases Risk of Breast Cancer in Daughters

by Nora Cody

RESEARCHERS at the National Cancer Institute have found that the millions of women whose mothers took DES while pregnant with them may have a significantly increased risk of developing breast cancer after the age of 40. Their study, published in the October journal *Cancer Causes and Control* compared 3,916 women who were exposed to DES in utero with 1,746 unexposed women. The study found that DES daughters over 40 were 2.5 times more likely to develop breast cancer. Previous studies have already found that women who took DES while pregnant—DES mothers—are 30% more likely to develop breast cancer than non-exposed mothers of their age group.

This does not mean every daughter is at high risk. The actual number of cases was 43 in the daughters and 15 in the unexposed group. Any case is one too many, but perspective helps us deal with this latest news.

An estimated 2.4 million DES daughters in the United States were exposed during the years 1938-1971. Most of them were born during the "baby boom" years of the 1950s and 1960s, so the majority of DES daughters are over the age of 40. The study found that there was no significant association between DES exposure and breast cancer for women under 40. The lead author, Julie Palmer, also reports that virtually all of the DES daughters with breast cancer were diagnosed with estrogen receptor-positive tumors.

"This report makes me both sad and very angry," notes Molly Berigan Spira, President of DES Action. "Many of us have lived in fear of hearing this news. We have many questions. How should DES daughters be screened and treated? Should they receive a different treatment protocol?" Spira said that she feels "anger at the drug companies who manufactured and promoted DES, who needlessly

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Still more questions on breast cancer

by Pat Cody

INSIDE

BREAST cancer is in the news on other accounts. A major study in China covered 266,064 women in Shanghai factories over an 11 year period, as reported in the October issue of the *Journal of the National Cancer Institute*. Half of them were taught breast self exam and the other half were not. The study investigators, led by Dr. David Thomas from the Fred Hutchinson Cancer Research Center in Seattle, state that they found no difference in the death rates between the two groups. They concluded that the efficacy of breast self exam "is unproven and that it may increase their chances of having a benign breast biopsy."

No sooner was this published than many women replied, in the media and the Internet, that their experience was different: their tumors were first found because they did self-exam.

Meanwhile, the controversy over the value of routine mammography screening continues. Recent studies have found no

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How to Join the DES Daughters Listserv

DES Daughters should check out DES-L, the DES daughters listserv and online support forum 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 1,000 other DES daughters! Note: this list is operated independently from DES Action.

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Yes–I want to get answers about DES. Enclosed is my membership.

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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Notes from Nora

Why isn't it more satisfying to be able to say "I told you so?" That's what we've been saying around the office in response to the recent news about Hormone Replacement Treatment (HRT), or what Cindy Pearson (Director, National Women's Health Network) calls "the triumph of marketing over science." But somehow, when millions of women have been made guinea pigs once again, saying those four words just doesn't offer much consolation.

In this issue we feature excerpts from testimony presented by Judy Norsigian on behalf of Prevention First, a coalition of independent health organizations of which we are a founding member. We thought that this statement, presented recently to a panel convened by the National Institutes of Health, contained so many important points relevant to how medical care really works today. Why were physicians so eager to embrace HRT, given the flimsy evidence that it conferred the many health benefits touted by its manufacturers? The parallels to the extensive use of DES are obvious. What's frightening is to think that the medical system has learned so little and that we must still practice such vigilance as consumers. ■

Why so Little News about Sons and Mothers?

WE sometimes get this question from DES sons or DES mothers disappointed that we don't feature more news about research affecting these groups. Our answer is: we would love to have more articles reporting about DES sons and mothers! But we are limited by the small amount of research devoted to these groups, relative to the attention given to DES daughters. This is not a function of the work of DES Action—in fact, it is due to our efforts that the National Cancer Institute added DES sons and DES mothers to their long-term follow-up study, nearly ten years ago. We have consistently pushed for research on all groups affected by DES exposure, and continue to do so. Data from the last five years of surveys in this study is being analyzed now, and reports will begin to trickle out over the next year or so (see, for example, the article on breast cancer and DES daughters in this issue). These reports will include some news about DES sons and mothers, even if it's only to confirm earlier data such as the link between breast cancer and DES in women who took the drug while pregnant. So stay tuned, and meanwhile please continue to share your concerns with us.

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.

DAUGHTERS STILL NEED EXAMS

Dr. Arthur Herbst was the first author on the landmark study in the *New England Journal of Medicine* for 22 April 1971 linking DES exposure to clear-cell cancer in DES daughters. Since then he has maintained a Registry for these cases. Although it is voluntary, and may understate the number of cases, it is the only systematic effort to document these cancers. An Australian Physician, Dr. Jules Black, asked him about case reports and here is Dr. Herbst's reply: "The oldest DES exposed patient to develop CCA had reached an age in her early 50s diagnosed, I believe, earlier this year. There are a number of CCA patients who are DES exposed and who were over age 50 years at the time of diagnosis. I believe the evidence from our Registry is quite clear and that these cancers will continue to develop, rarely, among the exposed. There clearly is no safe period. The DES exposed without CCA at a minimum need an annual pelvic examination."

Warnings from Workshop on Menopausal Hormones

by Pat Cody

LATE in October the National Institutes of Health sponsored a two-day scientific gathering to discuss the concerns about hormone treatment. Our last issued featured "HRT: Hazardous to Women's Health" with a full description of the findings from a long-term study on HRT that was abruptly halted because of what it showed on harmful effects.

At this October conference, the *New York Times* reported on 24 October that Dr. Rowan T. Chlebowski of the Harbor-UCLA Research and Education Institute stated that "even women who took the hormones for some period but then stopped had more breast cancer than those who never took the hormones. Their increased risk, the *Times* reported, was about equal to that reported for the entire study: hormone therapy would result in an extra 8 out of 10,000 women per year being found to have breast cancer...

"Dr. Chlebowski and others also cautioned against assuming that the risks of hormone replacement therapy end when a woman stops taking the drugs. He said other hormone treatments can have delayed and lasting effects. Women who take the drug tamoxifen, which blocks estrogen's effects in the breast, for five years and then stop, are protected from breast cancer for another decade, Dr. Chlebowski said. But tamoxifen also increases the risk of cancer of the uterine lining, and women who take the drug for five years and then stop are at increased risk for this cancer for another decade, he said."

The Prevention First coalition, of which we are members, presented a statement at this workshop by Judy Norsigian, editor of *Our Bodies Ourselves*. She pointed out that:

"Drug companies have created the false impression that women can avoid menopause and aging by taking HRT. Ads for HRT have paradoxically played on feminist sensibilities of personal power even as they promote the idea that it is important for aging women to take drugs so that they can look young. Encouraging women to fight back against aging and to take control of their lives, one ad for Premarin showed a youthful-looking older woman saying that HRT is 'Something I do for myself.' Another claimed that 'When it comes to menopause, your body is 100 years behind the times,' implying that modern women don't have to stand by and let their bodies age if they take HRT.

"And it wasn't just ads; companies have also been successful in securing unpaid, unregulated advertising for HRT through sophisticated manipulation of the media. *Parade* magazine, for example, put model Lauren Hutton on its cover for a piece on celebrity beauty tips, and quoted her saying her 'No. 1 secret is estrogen. It's good for your moods, it's good for your skin. If I had to choose between all my creams and makeup for feeling and looking good, I'd take the estrogen.' The article didn't mention that Hutton was a paid spokesperson for Wyeth Ayerst, and that she appeared in their ads. It also didn't mention that Hutton's claims for estrogen's

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benefits were not backed up by valid scientific evidence."

We need to keep these warnings in mind as the makers of dietary supplements, which do not require FDA regulation, are stepping forward to promote their products. The *Wall St. Journal* reported on this in a story by Andrea Petersen in their July 24 issue:

"With millions of women deciding whether or not to continue taking estrogen and progestin pills, a wide array of companies that sell everything from herbs to creams to acupuncture are ramping up marketing efforts with videos, speaking tours, physicians' office visits and glossy advertising campaigns."

In a sidebar to this article, the *Journal,* under the heading of "Alternatives to HRT", had this to report:

"While many of the products have been used for decades (even centuries) by European and Asian women, there are few independent U.S.-based scientific studies to support their safety and efficacy. Some top therapies and the available evidence:

"Substance: Black cohosh. Evidence: Studies have shown a reduction in hot flashes; NIH is investigating its effect on bone and hearth health and mood. Side effects: Minor stomach upset.

Soy. Evidence: Studies have shown lowered cholesterol. May also reduce hot flashes and help with bone health. Side effects: some doctors are concerned that long-term consumption of large amounts could increase risk of breast cancer.

Dong quai. Evidence: Widely used in Asia to reduce hot flashes and help with cardiovascular health. No rigorous independent U.S. studies show efficacy. Side effects: May be toxic. Can cause bleeding and sensitivity to the sun.

Evening primrose. Evidence: may reduce night sweats. No rigorous trials show reduction in hot flashes. Side Effects: No long-term safety studies."

Some watch-words from the National Women's Health Network follow on page 6. ■

CDC'S DES UPDATE

The Centers for Disease Control's DES Update, the national program for health care providers and the public, is finally ready to launch. We expect to have publications and a website to announce by the end of this year. DES Action is working closely with the CDC to help disseminate the DES Update materials and to work to promote the Update to local media outlets. We need your help!

Anyone can help disseminate these materials. Those with particular access to media can also help us with contacts or leads. If you'd like to help, please call me (1-800-DES-9288), send an email (desaction@earthlink.net) or drop me a note (610 16th Street, Suite 301, Oakland, CA 94612). I'll be keeping a list of everyone who wants to help and getting back in touch with you when the DES Update is ready to go.

Once the informational materials are available, you will be able to call a toll-free number at the CDC and request that the materials be sent to you or to your health care provider. We'd like for you to contact DES Action, too, to let us know you want to help spread the word and so that we can keep track of which health care providers are being kept informed, and which communities are participating.

FALL BOARD MEETING NOTES

DES Action recently held our fall Board of Directors meeting just outside of Manhattan, in Teaneck, New Jersey. We discussed our plans for the next six months, passed our budget and reviewed significant projects. We also elected Stephanie Kanarek of New York City to the Board, and held officer elections. The officers of DES Action are: President: Molly Berigan Spira (Utah); Vice President: Mike Freilick (New Jersey); Secretary: Barbara Tunick (New Jersey); Treasurer: Fran Howell (Minnesota).

Significant projects include the CDC's DES Update, which will occupy many of our board members and local contacts this year, and our ongoing participation in the Prevention First Coalition. We also plan to expand our Endocrine Disruptors project, to build awareness of DES as an endocrine disrupting chemical and to develop our networking with environmental and health organizations regarding this issue.

Congratulations are due to Board member Jean Golomb, DES Action coordinator for the state of Pennsylvania. Jean recently obtained a grant for $50,000 to extend last year's radio campaign about DES to the rural areas in the state. Jean has a tremendous amount of initiative and has shown that an organized and persistent constituency can accomplish great things. Members in Pennsylvania can expect to hear about DES on their radios in the coming year.

Protecting Your Health:

How to evaluate the next "miracle drug" for women

Ask these questions when you hear about drugs or alternative products claiming to address a problem associated with menopause:

1. **Will you be able to tell if the product is working?** If you have symptoms like night sweats or hot flashes, you'll be able to tell, because either the troublesome symptom will stop or it won't. But if you're taking the product to improve your health without relieving specific symptoms, demand solid evidence that the product actually works in a situation like yours.

2. **What kind of studies have been done?** Any new product should be backed up with studies comparing it either to a placebo or to another standard treatment. Ideally, the study should assess the effects on a large number of people. The more serious the benefit that is claimed, the longer the studies should last. Look for the word "randomized."

3. **Just what do those numbers mean?** Drugs and other products are often described as "cutting incidence in half" or "reducing risk by 30%." But if the condition only happens in 3 women out of every 100 treated, and the risk is reduced by 30%, the absolute benefit is only 1%. Look for information that describes the product's impact in terms of how many women are affected in every 100 or 1,000.

4. **There's (almost) always a risk: What is it in this case?** With the possible exception of water-soluble vitamins, all health products have risks, including herbs, dietary supplements, "natural" hormones and prescription medicines. Find out what is and isn't known about the risks so you can determine whether any possible benefit outweighs those risks. Again, look for the numbers. Make sure that both risks and benefits are described in the same numerical terms, either as percentages or as raw numbers.

5. **Who has a stake in your decision?** Is the expert quoted by the media a researcher for this company? Is the celebrity talking about how important it is to be "aware" of a new health condition paid by a company that sells a remedy for that condition? Are those brochures in your doctor's office produced with drug company money? (Look for the words "unrestricted educational grant" in fine print on the back of the brochure.) And be wary.

From the National Women's Health Network
www.womenshealthnetwork.org

DES INCREASES RISK from page 1...

exposed millions of women to this toxic drug for the sake of their profits."

A standard treatment for women with estrogen receptor-positive tumors is treatment with the drug tamoxifen. Tamoxifen, like DES, is a SERM (selective estrogen receptor modulator), and is sometimes given to healthy women to reduce their risk of developing breast cancer. It is not known if exposure to tamoxifen carries risks for DES daughters that are greater than those for non-exposed women. Barbara Brenner, Executive Director of Breast Cancer Action, called for extreme caution in using tamoxifen to treat DES exposed women with breast cancer or to reduce their risk of the disease. She notes that "The DES experiment with women's lives should not be compounded by exposing women to another SERM in connection with breast cancer. We need to know whether doing so is safe before we start down this road."

There is no uniform approach to medical care for DES daughters. Indeed, many health care providers do not even screen for DES exposure on medical intake forms. We have called on the government to use all possible means to urge all health care providers to screen for DES exposure and to set up a new research project to develop the best treatment protocol for DES daughters with breast cancer. We must make sure that these cancers are properly tracked, appropriately treated, and that DES exposure is identified in each case. The cancer reporting system is not currently equipped to identify DES exposure in breast cancer cases. This must be changed. We also want Congress to increase funding to the Centers for Disease Control and Prevention for their DES Update, a public education program directed at health care providers and the public. ■

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reduction from mortality resulting from mammography screening of women under 50. But then a recent Swedish study in the journal *Cancer* states that mammography *does* reduce breast cancer deaths. In a press release, Barbara Brenner from Breast Cancer Action notes that:

"Women diagnosed with 'early' breast cancer fall into one of three groups...One group has a type of slow-growing disease that will never be life threatening, for whom administered treatment is unnecessary. Another group has highly aggressive disease that, no matter how small it is when diagnosed, cannot be effectively treated with currently available therapies. (These women will eventually die of breast cancer no matter what treatment they are given, unless they die of something else first). A third group of women respond to currently available treatments, and finding breast cancer earlier does increase the likelihood that treatment will work for women in this group.

"We need to acknowledge the complexity of breast cancer. And we need to keep working to develop new methods of diagnosing breast cancer that are not radiation-based, as well as effective treatments for the people we cannot currently treat, and ways to distinguish those who will benefit from treatment from those who won't."

The noted authority Susan Love, author of *Dr. Susan Love's Breast Book,* sums up a position that makes sense. In an article in the *New York Times* she points out:

"For example, all the current tests—mammography, MRI, ultrasound and thermography—look for the presence of cancer tumors. But what we need to do is get in earlier in the process of malignancy. We need to be able to find cells that are abnormal but have not yet become cancerous...It's time to move beyond the debates about the utility of breast self-examination and mammography and increase the resources and energy devoted to finding something that will truly give us early detection." ■

We Lose a Friend

We extend our sympathies to the family of Rep. Patsy Mink (D-Hawaii), who passed away in September, and whom we profiled in our Summer 2001 issue 89. Ms Mink was a DES mother and one of the plaintiffs in a 1977 lawsuit against the University of Chicago Medical Center. She had been one of the women in the landmark Dieckmann study on whether DES was effective in preventing miscarriage. She and two other mothers were the named plaintiffs in a class action suit brought by the Public Citizen's Health Research Group against the University.

Dr. Sidney Wolfe, director of that group, writes that "In the context of that lawsuit we became aware of the NCI-funded mothers' follow-up study, which resulted in our obtaining and making public previously unpublished data showing a significant increase in breast cancer in DES mothers, compared to mothers given a placebo."

Rep. Mink's activity on behalf of the DES community was also shown in her support for legislation that provides funding for DES research and education. And, in 1994, when manufacturers were trying to pass a "Tort Reform" bill that would limit our access to the courts, she spoke on the floor of Congress for us:

"There is no doubt whatsoever that DES has caused irreparable injury to millions of children. They should be allowed to sue for damages under basic principles of tort liability. DES exposure is a continuing threat, and at any point when it results in cancer or any other life threatening consequence, the parties responsible should be held accountable...If the harm they suffered was caused by willful and wanton behavior, by what right does the Congress deny them punitive damages?"

Rep. Mink was a friend to women, to her constituency, and to the DES community. She will be missed. ■

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