DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

Issue #29 **Summer 1986**

NCI Encourages Studies on Breast Cancer in DES Mothers *and* Daughters

Many questions remain to be answered about health risks related to DES exposure—that is not news. There is news, however, about recent steps taken by the National Cancer Institute (NCI) to answer some of those questions. The Division of Cancer Prevention and Control of NCI, through the Organ Systems Program (Breast Cancer), has just announced that it is inviting proposals for research on a number of questions pertaining to DES and breast cancer. Applications for studies on breast cancer in both DES-exposed mothers *and* daughters will be accepted.

The NCI action constitutes official recognition of the scientific and medical importance of this topic as a research priority. One major focus will be on additional follow-up of DES mothers; recent studies report 40% excess risk of breast cancer in DES mothers, and raise questions needing further investigation (see *Voice* Issue #23, Winter 1985). In addition, the NCI is inviting proposals designed to study whether DES daughters are more likely than non-exposed women to develop breast cancer. This question could not be studied adequately until the present time, as DES daughters are just now reaching the age when breast cancer begins to appear among all women. As the NCI document noted, **"the biological rationale for increased risk of breast cancer from DES exposure exists for daughters exposed *in utero*, as well as for mothers."** Clearly, it is essential that we learn as much as we can about this possibility, to determine whether DES daughters do, in fact, experience increased rates of breast cancer. Only with such information can DES daughters then seek appropriate breast screening as they grow older.

Progress toward further studies of breast cancer in DES-exposed women is an outgrowth of a January 1985 DES Task Force meeting, for which DES Action served as consultant. This meeting was convened by the U.S. Department of Health and Human Services, following publication of the findings on breast cancer in DES mothers, and of the findings on increased rates of cervical and vaginal dysplasia and carcinoma *in situ* among DES daughters (see *Voice* Issue #23, Winter 1985). With regard to breast cancer, NCI scientists have now identified a number of issues to be addressed through further research:

1) Is there an increased incidence of breast cancer in DES-exposed individuals relative to appropriate comparison groups? If yes, can DES be clearly determined as the cause of the increase? Or, for example, might women who were given DES have had reproductive problems that are a more direct "cause" of later development of breast cancer? (Of course, an answer to this question would not alter the increased risk of breast cancer for DES mothers.)
2) What distinguishes DES-exposed women who do develop breast cancer from those who do not? How do the women compare with regard to dosage, timing and duration of treatment, as well as the reasons for DES treatment? Does a combination of DES exposure and other factors (i.e. exposure to other hormones, a family history of breast cancer and/or certain endocrine conditions) make more likely the development of breast cancer?

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INSIDE:

Get Into the Action

DES Action USA could not have originated and grown without the dedicated efforts of volunteers. Today, we proudly boast the activities of over forty DES Action groups around the country and around the world. The foundation of each group was created and nurtured by volunteers. *We still need you.*

Write your group today. Offer your services for a few hours a week. Become a part of the action with DES Action.

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Breast Cancer *continued...*

3) What type(s) of breast tumor are seen in DES-exposed women, and does the breast cancer differ from that seen in non-exposed women?
4) Is there an increased incidence of benign or pre-malignant breast lesions in DES-exposed individuals, and what are the characteristics of any such lesions, especially in women who subsequently develop breast cancer?
5) What other cancers are developing in DES-exposed mothers or daughters, and what is the time relationship between appearance of these and development of breast cancer and/or pre-malignant breast lesions?

Currently, NCI funds only one grant for research on the role of DES in human breast cancer, and no grants for animal studies.

The NCI program announcement on breast cancer is certainly a positive, much needed development. Unfortunately, there is no guarantee that funding will actually become available to support the invited proposals. Present budget-cutting efforts in Washington, D.C. threaten DES-related studies, along with other medical and biological research. DES Action supporters know only too well that public pressure has been necessary to obtain governmental action regarding DES exposure—including the 1985 Task Force meeting and issuance of the Task Force report, which became the basis for the current NCI action. While encouraged by this recent movement on NCI's part, we will need to monitor further action, not only on the breast cancer issue, but also on the many other remaining questions about the health of DES-exposed women and men. ■

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Drug Pushers—Government Approved

In a conflict shaping up between Third World countries and the $100 billion a year international pharmaceutical industry, the United States appears to be moving in the direction of the multinational pharmaceutical firms, many of which are U.S. owned.

The controversy centers around efforts by the UN World Health Organization (WHO) to restrict drug sales to the Third World. Consumer activist groups such as Health Action International (HAI) are actively working to advocate a WHO marketing code to restrict the number of drugs sold in the Third World. And, in order to conserve scarce health funds, WHO wants to bar even safe drugs from Third World markets when there are cheaper or more effective alternatives. The pharmaceutical industry, with annual Third World sales of $15 billion, opposes any such restrictions.

"The marketing and distributing practices of pharmaceutical companies need to be regulated and controlled."

Many drugs are sold in underdeveloped countries, after they are shown in the U.S. to be ineffective or harmful. DES is still being given to pregnant women in countries other than the U.S. Drugs are also marketed that are seemingly harmless in the U.S. or Europe but may have deadly consequences in Africa or Asia, when used, ineffectively, to treat conditions not found in industrialized nations, thereby avoiding other, more effective treatment.

DES Action USA is affiliated with HAI, through DES Aktiegroep, The Netherlands, which is part of DES Action International. During the 1985 UN Decade for Women Conference in Nairobi, Kenya, DES Action met with members of HAI and other health activists from around the world. We felt a real sense of achievement when the "Forward Looking Strategies" document of the Conference included our amendments. These additions to the section on Women and Pharmaceuticals state as follows:

"Efforts should also be made to eradicate the marketing and distribution of unsafe, ineffective and overpriced drugs. These efforts should include educational programmes to promote proper prescription and informed use.

"The 'UN Consolidated List of Products, whose Consumption and/or Sale have been Banned, Withdrawn, Severely Restricted or Not Approved by Governments,' should be used as a reference by all governments. Also, all governments should adopt a National Drug Policy, including the implementation of an essential drug list. When drugs are imported or exported, governments should use the WHO Certification Scheme on the Quality of Pharmaceutical Products Moving in International Commerce.

"The marketing and distributing practices of pharmaceutical companies need to be regulated and controlled."

Health Action International representatives have pointed out that international rules are needed because most underdeveloped nations cannot afford to police the drug industry by themselves. They can afford little or no research into drugs, relying instead on such agencies as the U.S. Food and Drug Administration to make sure medicines are safe and effective.

It is, therefore, distressing to learn that the U.S. Senate, by a vote of 91 to 7, recently agreed to allow the export of U.S. drugs that have not been FDA approved for safety and efficacy. Senator Howard Metzenbaum, D-Ohio, the chief opponent of the bill, said that if the House also passes this bill, U.S. drug manufacturers will be given a blank check in their exports to the Third World. Supporters of the bill state that it will return jobs to the U.S. and that it is 'arrogant' for the U.S. to control drug sales to other countries. The bill would repeal a Federal law in effect for nearly half a century that bars export of most prescription drugs unless they have been approved by the Food and Drug Administration. (The dumping of drugs found harmful *after* approval by the FDA would not be affected by passage or denial of this bill.)

The knowledge we gained in Africa about the prescription and over-the-counter sale of U.S. drugs and the inability of poor countries to do any studies of their own leads us to support Senator Metzenbaum's efforts. We know from experience what happens when poorly tested drugs are put on the market. We want to see that such drugs do not bring sorrow into the households of any other families, **wherever they live.** *Voice* readers are urged to let your Congressional representatives hear this point of view. ■

PMS Backlash

by Sadja Greenwood, M.D., M.P.H.
Reprinted, with permission, from Medical Self-Care Magazine

Warning! Your doctor's treatment for your Premenstrual Syndrome (PMS) symptoms may be dangerous to your health. PMS—the headaches, irritability, fatigue, anxiety, bloating, weight gain, breast tenderness and appetite changes associated with hormonal changes in the menstrual cycle—has become a hot topic in the media. The recent PMS publicity has broadened women's awareness about their bodies, but it has also painted a negative and exaggerated picture of the menstrual cycle. Menstruation, under the PMS label, is once again "the curse," and a flood of books, remedies and PMS clinics have appeared, all touting "cures" for this menstrual malady. In what I call "PMS backlash," the medical community has come up with several "PMS cures"—powerful and potentially dangerous drugs whose long-term side effects are largely unknown.

Little is really known about PMS. The multiplicity of symptoms has made it difficult to define the syndrome and to determine its cause. Despite this lack of information, medical researchers and physicians are moving full speed ahead with treatments that rely on potentially hazardous drugs.

One of the first to advocate drugs to treat PMS symptoms was the English physician Katharina Dalton. In *Once a Month* (Hunter House, 1978), Dalton writes, "Once a month with monotonous regularity, chaos is inflicted on American homes as premenstrual tension and other menstrual problems recur time and again with demoralizing repetition." She goes on to describe the menstrual cycle as "incapacitating," something that can only be managed by "parents, husbands and doctors." Once she has convinced women they are powerless to cope with their menstrual problems, she asserts that PMS can be "cured" with progesterone. Progesterone, an ovarian hormone taken daily before the period through injection, vaginal suppositories or rectal solution, has questionable effectiveness for PMS symptoms and its long-term side effects have not been rigorously studied. Two double-blind studies comparing progesterone and placebos found the hormone ineffective against PMS. Although the FDA has not licensed progesterone as a PMS treatment it is widely prescribed nonetheless.

Another drug proposed to treat PMS is bromocriptine (Parlodel). This powerful drug mimics the action of the neurotransmitter dopamine, a hormone with far-reaching effects on the central nervous system, particularly affecting mood. Bromocriptine is currently licensed to treat such problems as pituitary tumors and Parkinson's disease as well as to suppress lactation after childbirth. The drug may significantly lower blood pressure and produce dizziness. In some cases it has the opposite effect of elevating blood pressure. Long-term treatment has been associated with lung problems.

Another drug, spironolactone, a diuretic and antihypertensive medication has been used for PMS symptoms. Spironolactone's side effects include drowsiness, headache, irregular menstrual periods, body hair growth and deepening of the voice. There is also a suspected spironolactone-cancer link. To administer these potentially hazardous drugs month after month to women for PMS symptoms seems an obvious medical overreaction.

The most powerful and frightening PMS remedy is GnRH, Gonadatropin Releasing Hormone, currently being tested on women with PMS symptoms. GnRH is the key brain hormone that regulates the entire reproductive system. Administered as a nasal spray, a new drug similar to GnRH causes reversible premature menopause. An article in the *New England Journal of Medicine* called the drug the "first rational treatment" for women with PMS because it eliminates ovulation and the hormonal fluctuations associated with PMS symptoms.[1] That's like cutting off the arm to treat a splinter.

Natural Alternatives

There are safer alternatives for women who suffer monthly PMS. Two excellent self-help books are Dr. Michelle Harrison's *Self-Help for Premenstrual Syndrome* and *Dr. Susan Lark's PMS Self-Help Book: A Woman's Guide to Feeling Good All Month* (see Resources). Both Harrison and Lark assert that most women's PMS problems can be managed through simple, healthful lifestyle changes. Some of their recommendations include: a balanced diet which incorporates plenty of fresh fruits and vegetables, whole grains and lots of water; eliminating or cutting back on caffeine and sugar; diuretic teas to counteract bloating; regular aerobic exercise; stress reduction techniques such as meditation, T'ai Chi and yoga; counseling; planning time alone; meeting with other women in PMS self-help groups; maintaining a PMS journal to understand and anticipate symptoms; and vitamin and mineral supplements, particularly vitamin B6 (200 mg/day), calcium and magnesium.

These simple lifestyle approaches provide relief for many women with PMS. They should certainly be tried *before* resorting to powerful drugs with myriad side effects. And doctors should take a hard look at their over-dependence on potentially dangerous drugs to treat problems associated with women's normal physiological cycles. As the Greek physician Hippocrates warned doctors, *"Primum non nocere"*—"First do no harm." ■

Reference

[1]Muse, Ken M., M.D. et al., "The Premenstrual Syndrome: Effects of 'Medical Ovariectomy'," *The New England Journal of Medicine*, p. 1345, Nov. 22, 1984.

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Dear Doctor

Thanks to ***Grannum R. Sant, M.D., F.A.C.S.,*** *for answering our* ***Dear Doctor*** *question. Dr. Sant is Assistant Professor of Urology and Director of Endourology at Tufts University, School of Medicine, New England Medical Center, Boston, Massachusetts.*

Q: I am a DES son, and even though I have known about my exposure for several years, I have never made an appointment with a urologist. Is there a special genitourinary tract exam for DES sons? How often should I go to the doctor? How often should I do testicular self-examination? Is there anything that I should know regarding infections or other problems of the prostate?

A: DES exposure has been reported as predisposing to an increased incidence of a variety of genitourinary tract disorders including undescended testes, small testes, epididymal cysts and infertility. The exact incidences of these abnormalities is difficult to ascertain but all DES-exposed sons should have a careful urologic examination. This examination can initially be done by the family practitioner and should include examination of the testes, spermatic cords and a rectal examination. If there are any abnormalities encountered, a urologic referral is suggested.

All males are advised to have frequent, testicular self-examination and this applies more particularly to males exposed to DES. This examination is easy to do, takes a few minutes and should be done at monthly intervals. If any testicular lumps are felt, then a a physician or urologist should be consulted immediately. Possible lumps can be evaluated both clinically and radiographically using scrotal ultrasonography. The ultrasound can diagnose testes tumors, epididymal cysts and varicoceles.

The role of *in utero* DES exposure in relation to male infertility is not clear. However, all DES-exposed males who are considering becoming fathers should undergo a thorough examination of the scrotum and a semen analysis.

Infections of the prostate and other parts of the genitourinary tract have not been reported to occur with more frequency than with the general population. However, if there are signs of infection such as urinary frequency, pain on urination, scrotal pain, etc., urologic consultation is advised. ■

Letter to the Editor

I recently attended my first meeting of DES Action in Framingham, Massachusetts, October 25-27, 1985. Several issues brought up at this meeting have directly affected my life.

My mother was given DES when she was pregnant with me in 1953. I was born prematurely, and at one point weighed only two pounds. I was also born with a heart murmur which was corrected by surgery when I was thirteen.

In January of 1983, I developed testicular cancer. My left testicle was removed, but the cancer had already spread into my lymph nodes. I needed chemotherapy and more surgery to remove the tumors. In May of 1984, a large tumor appeared above my bladder. I went through more chemotherapy, and in September of 1984 had surgery, which lasted eight hours, to remove the tumor. At the time of this letter, it has been over a year since my surgery and I am healthy.

The first time I was sick, in 1983, I really didn't talk to anyone about these issues. When my illness came back in 1984, I did talk to people during and after my treatment and surgery. I believe this is one reason I am alive today. By talking with other men about testicular cancer and other DES-related issues, it has helped me confront and face my illness. It has helped me try to put my illness in the past.

At the DES meeting, I was nervous at the beginning. However, the openness of the women in discussing their issues related to DES made me more comfortable in discussing my own issues. At times during the meeting I laughed, at other times I cried. I could identify with many of the issues the women had discussed, especially the women who had gone through cancer. Even though women are biologically different from men, these DES issues affect us in similar ways. In most cases, we are affected sexually.

If women who are affected by these issues are willing to come out in the open and discuss their personal lives, then there is no reason why more men can't do the same. The women I met at this DES meeting showed great strength and courage, and hopefully more men will come forward to discuss these issues and show the same thing.

If I can be of any help in discussing male-related DES problems, I can be reached at the address below. Perhaps a male DES telephone hotline could be established to help us talk about these issues.

Again, I enjoyed meeting everybody at the meeting.

Thank you,
Michael Freilick

DES Sons Network

c/o Michael Freilick
1200 E. Marlton Pike #505
Cherry Hill, New Jersey 08034

or Francis Lawler
DES Action Pennsylvania
P.O. Box 6
Lenni, PA 19052

Paradoxes of Reproductive Technology

In the Spring Issue of the *Voice*, parallels between the promotion of DES more than 30 years ago and the promotion today of in vitro fertilization (IVF) were highlighted by Anita Direcks of *DES Aktiegroep, The Netherlands.* Her article concluded with the irony and the concern that DES daughters, victims of the reproductive technology of a generation ago, are prime candidates for today's reproductive technology, due to the flaws of that earlier technology.

Indications for and the outcomes of in vitro fertilization, at the center of research in reproductive technology, were discussed in Ms. Direcks' article. Since publication of her article, there have been reports of the first birth of a child conceived in vitro where the embryo was then implanted, not in the woman whose egg was fertilized (because she had had a hysterectomy), but in the uterus of a surrogate mother. The surrogate mother gave birth to the child, who was then turned over to her genetic parents. A court ruling a month before the birth declared this couple to be the legal, biological parents. But, the reverse is also possible: a woman unable to ovulate would receive an embryo from a donor egg combined with her own partner's sperm so that she could give birth. Presumably, legal declaration that the resultant child was the child of the carrier and of the genetic father could and would be sought.

Restricting health care to only those who can afford it is an idea whose time has passed.

So, added to the medical, social and ethical issues, are the legal questions, which are becoming increasingly complex. Now, a fifth area of concern has recently begun to surface: insurers are attempting to avoid payment for infertility procedures. They claim that such treatment is "not medically necessary for the care and treatment of an illness, injury or pregnancy," as most policies' limits are stated.

As the baby business continues to boom, so the medical, ethical, social and legal questions multiply and yet, go unanswered.

Sometimes, insurance companies insist that a procedure does not correct a condition. According to the *New York Times,* the Travelers Companies have issued a memo saying that artificial insemination and in vitro fertilization are excluded from normal coverage. "We are taking the position that our contracts only provide for the care and treatment of a disease or injury. And these sort of treatments do not ameliorate the condition," said a Travelers representative.

Other companies maintain that procedures such as in vitro fertilization are still experimental and unproven as appropriate treatment for fertility, so therefore cannot qualify for coverage under the normal terms of a policy. According to a Blue Cross and Blue Shield administrator, the *Times* noted, "Our contracts do not permit us to pay for treatment that is still considered investigative."

These are serious decisions on the part of the insurance industry, since costs generally reach $5,000, and more, per procedure. Physicians are supporting the cause of their patients, and, in some cases, have been able to change decisions of individual insurers by explaining the reason for and importance of a treatment, and by explaining the treatment or surgery in gynecological rather than fertility terms. As quoted in the *New York Times*, Dr. Charles B. Hammond, Chairman of the Department of Gynecology and Obstetrics at Duke University Medical Center, was able to persuade one company to provide IVF coverage after demonstrating that surgery, which was fully covered, would probably not help in one woman's case, while IVF might be more successful.

Thus, we have the paradox of ever increasing technical skills which tantalize infertile couples with possibilities; while at the same time, the means to pay for such assistance is pulled away. Restricting health care to only those who can afford it is an idea whose time has passed.

This paradox is added to the already long list: as the baby business continues to boom, so the medical, ethical, social and legal questions multiply and yet, go unanswered. As individuals comtemplating in vitro fertilization, and as a society, we need to look beyond the technological developments and address the implications of reproductive technologies. We also need the opportunity to exercise our options without being constrained by insurance companies and others who would determine our choices. ■

PMS *continued...*

Resources

Self-Help for Premenstrual Syndrome by Michelle Harrison, M.D., 1985. $9.95 from Random House, 201 East 50th St., New York, NY 10022.

Dr. Susan Lark's PMS Self-Help Book: A Woman's Guide to Feeling Good All Year by Susan Lark, M.D., 1984. $12.95 from Forman Publishers, 11661 San Vincente, Suite 206, Los Angeles, CA 90049.

Sadja Greenwood is MS-C's Women's Health Editor. ***Medical Self-Care*** *teaches basic medical skills, stressing the advantages of exercise and nutrition, and advises how and when to use a health professional. Their address is:*

Medical Self-Care
P.O. Box 1000
Point Reyes, CA 94956

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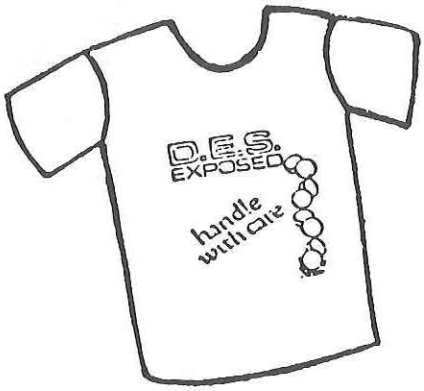

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The *Voice* is mailed out quarterly—the first week of January, April, July and October. New subscriptions received between the first of the month prior to the month of publication (that is, the first of December, March, June and September) and the date of publication will begin with the immediately following issue. New subscriptions received before that period will begin with the current issue. A year's subscription is four issues of the *Voice*.

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I am a ☐ DES Daughter ☐ DES Son DES Mother ☐ Other

Awareness Week 1986 Focuses on Reproductive Issues for Daughters

With activities ranging from Governor Proclamations to symposiums and guest speakers, to radio talk shows, DES Action chapters throughout the country proclaimed the week of April 20-26, 1986, "DES Awareness Week."

Highlighted by publication of DES Action's new booklet, **Reproductive Outcomes in Women Exposed *in utero* to Diethylstilbestrol: A Review of the Literature, 1978-1984,** thousands of people were reached with information on their possible DES exposure. Letters continue to arrive in the national DES Action office from people who are requesting, for the first time, information about DES. Through individual outreach and public meetings, people were given information on infertility, the choice of being child-free and reproductive problems experienced by many DES daughters.

DES exposure continues to be a problem for many. This year's Awareness Week pointed to the questions many DES daughters and sons are asking, now that they are considering the possibility of childbearing. Through DES Awareness Week 1986, many of the answers to those questions were provided and attention was brought to the importance of resolving those still unanswered.

DES Action International Annual Meeting Set

DES Action's first international Annual Meeting will be held September 26-28, 1986, in Toronto, Ontario, Canada. The meeting will focus on providing organizational skills to members of DES Action chapters throughout the United States, Canada, The Netherlands and Australia.

As with past DES Action USA Annual Meetings, there will be workshops on topics such as DES Exposure and Menopause, New Reproductive Technologies, Effective Counseling of the DES-Exposed, Currently Recommended Care for DES-Related Conditions and The International Work of DES Action.

Support groups will provide time to share personal experiences as well as to lend and gain strength from being with other DES Action volunteers who have similar concerns.

If you are interested in attending this exciting DES Action International Meeting, please contact DES Action/Canada, Room 442, Burton Hall, 60 Grosvenor Street, Toronto, Ontario, M5S 1B6, Canada.

DES Action USA

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