V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Winter 1991

#47

Estrogen Link to Breast Cancer

ne of the largest and longest studies ever done on whether post-menopausal hormones (ERT) increase the risk for breast cancer shows that there is a significant increase for current users of such ERT. Researchers at Harvard Medical School surveyed 118,273 nurses who were 30-55 years of age at the onset of a ten year study, from 1976 to 1986. They found that past users of ERT were not at increased risk, but current users had a risk 36% greater than the risk for a non-user of ERT. Total dosage, which in this study ranged from 0.3 milligrams daily to 1.25 milligrams daily, did not significantly affect the risk factor.

This study corroborates another study that followed 11,468 post-menopausal Seventh Day Adventist women for six years. In that study, reported in 1989,

current use of ERT was associated with a significant increase in risk for breast cancer of 69%.

The Harvard researchers concluded that "Although some studies with relatively sparse data have suggested an increased risk with long duration of use, we observed no effect of duration of use of estrogens on risk of breast cancer. The lack of a duration effect suggests that estrogens may act acutely to increase risk and that this effect is reversible within perhaps two years of cessation."

"These data...suggest that estrogen is a promoter of mammary tumors...However, the magnitude of increase in risk appears quite modest. Given the beneficial effect of postmenopausal estrogen therapy on the risk of cardiovascular disease and hip fractures, Henderson et al concluded, in a risk-benefit

analysis allowing for a relative risk of 1.5 for breast cancer with long-term (greater than 20 years) use of postmenopausal estrogens, that the benefits of estrogen supplement therapy markedly outweigh the risks. However, our data suggest greater complexity; elevated risk of breast cancer may appear before 20 years of postmenopausal hormone use but rapidly decline with cessation of use. Though this increase in risk will be counterbalanced by the cardiovascular benefits, these data suggest the need for caution in the use of estrogens."

Colditz et al, "Prospective Study of Estrogen Replacement Therapy and Risk of Breast Cancer in Postmenopausal Women," Journal of the American Medical Association, November 28, 1990.

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Freedom to Sue in Florida

lorida is the sixth state whose Supreme Court has ruled that DES daughters can sue the drug companies even if they do not know which manufacturer produced the DES their mothers took. In March 1980, the California Supreme Court made legal history with its recognition that "as between an innocent plaintiff and negligent defendants, the latter should bear the

cost of the injury... In our contemporary, complex industrialized society, advances in science and technology create...goods which may harm consumers and which cannot be traced to any specific producer. The response of the courts can be either to adhere rigidly to prior doctrine, denying recovery to those injured by such products, or to fashion

Get Into 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 across 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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L.I.J. Medical Center New Hyde Park, NY 11040

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DES Action/Netherlands DES-Aktiegroep Wilhelminapark 25 3581 NE Utrecht The Netherlands FLORIDA from page 1... remedies to meet these changing needs...some adaptation of the rules of causation and liability may be appropriate...."

The Supreme Courts of New York in 1982, and of Wisconsin, Michigan and Washington in 1984, made similar rulings. Now Florida has joined them in what the lawyer for DES daughter Terri Conley describes as "a major breakthrough in modernizing Florida law."

The Florida court decision of 1 November 1990 states that: "We agree with the U.S. District Court for the District of Massachusetts... that 'the magnitude of the physical and psychological injuries which are at issue in DES cases counsels toward permitting a remedy under some form of a market share theory of liability.' We have recognized that, because of the delay between the mother's ingestion of the drug and the manifestation of the injury to the plaintiff, DES cases must be accorded different treatment than other products liability actions for statute of repose purposes...This Court has consistently recognized its 'contincontinued on page 6



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A Personal Story:

Chronic Fatigue Syndrome

by Cecelia Volk

am a 39-year-old DES daughter who was recently diagnosed with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS). This illness is now recognized by the Center for Disease Control in Atlanta and has a specific set of signs and symptoms.

I met this criteria by suffering from swollen lymph nodes behind my ears and in my groin, night sweats, low grade fevers, swelling and pain in my finger joints, sore throat and a fatigue that 12 hours of sleep would not relieve.

When all my blood work came back NORMAL, I thought I was losing what little mind I had left after two hard years of law school. For at least six months I had no energy and no enthusiasm for anything.

In 1973 I had a case of mononucleosis which is caused by the Epstein-Barr virus. Epstein-Barr may or may not be a causative agent for CFIDS. However, over 90% of the population has been exposed to Epstein-Barr by the time they are 30. In CFIDS (now identified as a retro-virus), as with mono, a recurrence of severe flu-like symptoms can occur in times of extreme stress. This is what happened in my case.

After reading an article about CFIDS in a popular magazine, I went to a physician who was a CFIDS "specialist." He drew blood for viral studies. Sure enough, I came up with a positive result. This finding did not surprise me because I knew of the connection between DES exposure and a weakened im-

mune system (VOICE #27, 37, 40). I have also heard that the healing process for DES offspring may be slower than for non-exposed people.

I want to alert my DES friends that if they are experiencing any of these symptoms, they are not just imagining them. They should contact a physician who is aware of CFIDS and can do appropriate testing procedures. Like DES, CFIDS is a chronic condition that we must learn to live with on a "one day at a time" basis. I am feeling better now, taking certain vitamins, swimming regularly, and letting things go that I don't absolutely have to do.

I found it much easier to accept that I was suffering from CFIDS and needed to alter my life style once I was able to get a correct diagnosis, and then empower myself with information about this illness. If you would like more information on CFIDS, you can write to:

CFIDS Society International P.O. Box 230108 Portland, OR 97223 National Chronic Fatigue Syndrome Association 33521 Broadway # 222 Kansas City, KS 66111 816-931-4777

Send self-addressed and stamped envelope for brochure. Patient information packet, \$3; other brochures available.

CFIDS Association, Inc. P.O. Box 220398 Charlotte, NC 28222-0398 704-362-2343

(They have physician referral lists).

** * dear doctor

I was diagnosed in 1983 as having a pituitary tumor although tomograms, two CAT scans, and an EMRI have shown no conclusive evidence of a tumor's presence. However, if I do not take Parlodel, I fail to ovulate and menstruate and I lactate continuously. My endocrinologist monitors my prolactin level yearly and tells me that I must stay on the Parlodel indefinitely—an insurance, he says, to help prevent osteoporosis.

Although I feel the Parlodel helped enable me to become pregnant twice, successfully (medication discontinued during pregnancy of course!), I am concerned about the long-term effects of taking this drug continuously. Have any studies or research been done on the long-term usage of Parlodel? What do DES medical advisors say? I also take synthroid for a hypo-thyroid.

The presence of a pituitary tumor can be heralded by either excessive hormone production or the evidence on a CT or MRI scan that it exists in the pituitary. The most common tumor that occurs in women is one that secretes prolactin. This is usually accompanied by absent periods and breast secretion. The functional elevation in prolactin secretion is much more common than the presence of a tumor, and hence it's unclear why the diagnosis in 1983 suggested a tumor when all the anatomic studies (tomograms, CAT scans and MRI) showed no tumor. I would take this to mean

Perspective on Breast Cancer: It's Not Just a Tragic Part of Life

by Ruth Rosen

hen does a disease become a political issue? When it is contagious, incurable and kills those who are still vigorous enough to mount a campaign to grab public interest and funding. Every year 140,000 women are diagnosed with breast disease; every year 42,000 women die of it. I am not the only person who, while watching one more television program on AIDS, has noted that every two years more women die from breast cancer than all the people in the United States who have ever died from AIDS. Yet because breast cancer is not a contagious or predictably incurable disease, and because women have not yet defined it as a "women's issue," what should be seen as a major social and political problem is regarded as a tragic and somehow biologically fated part of women's lot.

This is not to suggest that AIDS should receive any less attention or funding. On the contrary, women have a great deal to learn from groups that have successfully publicized and politicized the horror of the AIDS epidemic.

But it is time for national women's organizations to comprehend that a disease that afflicts so many women is more than a medical problem—it is a social concern entitled to the full force of national activism. What, for example, has caused the incidence of breast cancer to rise from one out of 11 women to one out of 10? Is it the result of better detection, longer life spans, or

It's time for feminists, the public and politicians to grasp that breast cancer is a disease of epidemic proportions that affects enormous numbers of women and, hence, hundreds of thousands of their children, partners and friends.

have environmental pollution, oral contraceptives and dietary habits somehow caused a greater proliferation of the disease? Why do so many doctors and insurance companies fail to encourage or cover preventive mammograms?

Because women are at particular risk, breast cancer is a women's issue waiting to be recognized as such. This doesn't mean that other problems, including abortion rights, are any less important. But a single-issue orientation has obscured the reality that breast cancer kills women with terrifying frequency.

In Cambridge and Berkeley, women who have survived cancer have started organizations (the Women's Community Cancer Project in Cambridge and the Women's Cancer Resource Center in Berkeley) to lobby for better preventive care, increased research funding, and improved insurance coverage, and to provide information and support groups for breast cancer patients. Other women, however, should

not leave this battle to those who are exhausted from treatment or in the process of dying.

The National Women's Health Network, a national organization that promotes and monitors women's health care delivery in the United States, has testified at congressional hearings that the government must reconsider its current priority of funding research for treatment while ignoring research for prevention. They are lobbying for the resumption of a canceled study on the association between dietary fat and breast cancer and for a new study to explore the connections between breast cancer and oral contraceptives.

There are many obstacles to overcome, including those in medical training. Only 2% of medical students take elective courses in preventive medicine; the academic award system rewards those who engage in basic research and technology development rather than those who devote themselves to prevention.

Attention to women's health care, moreover, is sadly neglected. In 1987 the National Institutes of Health spent less than 14% of its \$7.6 billion research budget on women's health issues, although women make up more than half the population. The General Accounting Office has reported that the National Institutes of Health have made little progress in including women in research study populations, and, as a result, women's problems are not taken seriously

Being a Volunteer—If Not Now, When?

By Andrea Goldstein

ccasionally people will ask me how I have stayed a volunteer for DES Action for so long, since 1977. Even my husband has remarked more than once that I "give" all of this time away and don't get paid for it. I'll be the first to admit that our family could use the extra income I would earn if I worked more hours at my "real" job. Lest you get the wrong impression, my husband is a blue collar worker and I work in the health care field. No Yuppie salaries here.

I had never heard of DES until the fall of 1971. I was 18 years old and just starting college. It was also the year when the link between prenatal exposure to DES and clear-cell vaginal adenocarcinoma was first reported. Of course, this was also the year when I went for a gynecological exam for the very first time. There was no DES Action then, and had there been, I doubt that as an 18-year-old, caught up in college life and dating, I would have given the existence of such an organization a second thought. I did, however, think a lot about being DES exposed. I worried that I would get "the cancer," that I would die, that I would never get married and never have children.

Not long after this, I remember being told by my doctor that I had a "pinhole" opening in my cervix. I asked if that would make it hard for me to become pregnant, and I remember his response: "If the menstrual fluid can get out, the sperm can get in." What neither of us could

have known at that time was that my strange cervical opening was but one outward manifestation of what had happened to my internal reproductive organs.

It was not until several years later, when I was married and experiencing infertility problems, that I learned of the extent of the damage done to my uterus and fallopian tubes by the DES. It was in June of 1977, with the realization that I would probably never be successful at bearing a child, that I sought solace in DES

"It was through DES
Action that I learned
what volunteerism was
all about, and that I could
be not just a beneficiary of
their help, but also a
benefactor to others."

Action, then a fledgling organization. It was through DES Action that I learned what volunteerism was all about, and that I could be not just a beneficiary of their help, but also a benefactor to others.

I immersed myself in DES selfeducation, and was horrified to learn that DES was known to cause cancer in 1938, before it had ever been given to human beings. I initiated a law suit against Eli Lilly, and during my trial was shocked and filled with disgust when I learned that a 1940 study on mice administered DES before their birth showed that with only one exception, all had congenital abnormalities of their reproductive organs; once again, before the use of DES in pregnant women.

Most of us are aware of the fact that asbestos is linked to health problems in those who worked with it. I don't know about you, but I never thought much about it. After all, I've been really caught up in my marriage, in raising my son, in adoption because that, too, is now a part of my life, and in my DES work, to name just a few of the things that vie for my time. Then in November of 1989, my father was diagnosed as having mesothelioma, the most devastating of asbestos-related cancers. My father had been a sheet metal worker, a shipyard worker, and later, the owner of a taxi company and garage where he made all his own repairs and changed countless brake pads.

I contacted the Cancer Information Service and the Asbestos Victims of America organization: I studied asbestos and its effects on health. I learned that it was known in 1898, twenty years before my father was born, that asbestos caused cancer. I was horrified to learn that protective clothing and masks could have prevented the tragic legacy of millions of asbestos workers.

Sitting at my kitchen table one day, I was struck by the similarities of the devastation taking place in my immediate family. First me, now my father: victims of corporate greed and the disregard for human life. Worse, while for me there was no treatment for my infertility, I could

DEAR DOCTOR from page 3... that there was functional hyperprolactonemia.

The problems encountered in this situation are typically either infertility or the lack of estrogen leading to osteoporosis and other menopausal-type changes. The use of Parlodel replaces the missing hormone (dopamine) controlling prolactin secretion, re-establishing menses, and stopping breast secretion.

For those patients wishing to get pregnant, it's obviously an appropriate ovulation induction technique as it was in this case.

The issue of how long to take the Parlodel still remains an open one. I think the word "indefinitely" reflects the current status. It's analogous to a patient with hypertension. When she's on her medication her pressure is under control, but she hasn't altered the underlying disease process. Once she stops her medication the hypertension returns. Similarly, the prolactin level will be under control, menses will occur and all the usual physiologic events are normal while taking Parlodel. When the Parlodel is discontinued, the underlying problem returns.

When a pituitary tumor is present, the use of Parlodel reduces the tumor size. It does not actually kill the cells, but reduces the volume of each cell and hence reduces the volume of the tumor. That has virtually replaced any surgical approach to tumor removal. With surgery, there's a high incidence of recurrence of the problem after tumor removal, so clearly Parlodel therapy is the most appropriate.

The drug has been available now for over a decade in the

United States and substantially longer around the world. As it mimics a natural hormone (dopamine), there are other analogous drugs which have been used for even longer intervals of time, notably L-Dopa. None of these have had major long-term effects although there are some concurrent side-effects such as nausea or postural hypotension that have been annoying. The only "research" that can be done on long-term usage of Parlodel is with long-term usage. I don't believe any patient has taken the drug over 25 years, so it will simply have to await clinical usage. All the signs to date, however, do not suggest any problems.

Hypothyroidism is frequently associated with increases in prolactin. They may be related or independent hormone abnormalities. When they're related, the patient with hypothyroidism has an elevated thyroid stimulating hormone (TSH). This can be easily measured in the blood. Upon thyroid replacement and lowering the TSH, the prolactin usually returns to normal and menses return. In situations in which the two are not linked, the prolactin will persist after thyroid replacement, so it's worth the trouble to investigate this possibility as it may cut down the number of drugs required.

Arthur F. Haney M.D.
Director, Reproductive
Endocrinology and Infertility
Duke University Medical
Center
Durham, N.C.



CANCER from page 4... until they reach a critical stage.

Look around you. One-tenth of your sisters, daughters, wives, lovers, mothers and female friends (who manage to survive other life-threatening accidents or diseases) will, in the course of their lives, receive a diagnosis of breast cancer.

It's time for feminists, the public and politicians to grasp that breast cancer is a disease of epidemic proportions that affects enormous numbers of women and, hence, hundreds of thousands of their children, partners and friends.

This is a silent political constituency waiting to be discovered. There is no greater human right than the right to live out one's natural life span.

Reprinted from the Los Angeles Times.

FLORIDA from page 2...

uing responsibility to the citizens of this state' to modernize traditional principles of tort law when such becomes necessary 'to ensure that the law remains both fair and realistic as society and technology change'."

This decision means that many DES daughters in Florida will be able to bring suit against the drug companies. It is important for other reasons as well.

- One-third of all DES-exposed people in the United States can now sue without product identification; this will have an influence on court actions in other states:
- The rights of consumers of all kinds of products are further safeguarded by not allowing manufacturers to escape responsibility under a shield of anonymity.

letters to the editor

want to thank you for the information sent to me by your organization and the help one of your telephone volunteers gave me in understanding the treatment of pregnancies of DES daughters. I was completely unaware of any risks with cancer or complications in pregnancy that DES could cause. Even all the reading I have done on pregnancy scarcely mentions DES or the problems associated with it. It is interesting that of all the gynecologists and obstetricians I have seen through the years, not one has questioned me about being exposed to DES, or educated me about the problems associated with it, when I mentioned it.

I am now beginning the fifth month of my first pregnancy. I have been to two doctors who had been very poor in their treatment of the pregnancy and interviewed several others who basically feel that I am making DES bigger than it is when requesting that the pregnancy be treated as high risk. "I could see if you

have had several miscarriages already..." have stated several doctors.

It has been very difficult to find an obstetrician who treats DES as high risk in my area. All the doctors here say they work with high-risk pregnancies but many refuse to treat DES as high risk. Some feel the risk doesn't occur until the fifth month, others don't believe someone my age (26) could have even been exposed to DES, and one had never heard of a stitch to treat an incompetent cervix and said he might treat the pregnancy with medication if I lose this first baby.

It may also be helpful for women to know that it is common to have been exposed even if there is no evidence of it on their mother's prenatal records. The charting done 30 years ago was not always very impressive. My mother's charts failed to record both the bleeding and the drug she was prescribed during her pregnancy with me. Fortunately, she kept records of

her own.

If I had not gone through heavy bleeding during my pregnancy or had doctors brush away my concerns about DES and an incompetent cervix, I would never have researched on my own and discovered the truth about it. I now question how thorough my previous pap smears have been. My concern is that there are many other woman who are in the dark as I have been. They trust their doctors to educate them and bring up concerns of which they are unaware. Why are doctors also appearing to be in the dark on this?

R.M. Dunedin, FL.

We share your views and are acting to increase awareness of DES by updating our physician referral lists for most states, and working on our Health Care Provider Education Project. We will be sending curriculum units on DES to medical, public health, and nurses' training schools.





Join DES Action!

es - I want to get the answers about DES. Enclosed is my membership

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ICS-IW	ant to get the answers about DE	5. Enclosed is my me	mbership.
□ Benefactor: \$1000 and above□ Sustainer: \$500□ Associate: \$250	□ Supporter: \$150 □ Friend: \$75 □ Subscriber: \$50-\$25 (sliding scale)	All members receive The DES Action Voice quarterly. Those at the \$75 level and above receive additional annual reports on DES	
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name			- DES Action USA
address			1615 Broadway, Suite 510

VOICI

VOLUNTEER from page 5... still have life. For my father, there was no treatment for his cancer, only the certainty that he would be lucky if he lived another full year.

I got my father involved in a law suit against the asbestos companies and became a member of the Asbestos Victims of America (AVA). I wanted to volunteer my time and knew that at some point I would. But this time, I realized my involvement would have to wait-I wanted to spend as much time with my father as I could, and I did, both through the "happier" times before his illness became so debilitating and then, toward the end of his life, helping to care for him at home. Indeed, when my father lost his battle with mesothelioma in November, I was with him.

As I write this, just 11 days since his death, the pain is great and the grieving is deep and real. But I cannot grieve to the exclusion of all else. As President of DES Action, I have already been in touch with the National Office to see that all is well. For me it was an honor and an act of love to do so, and not an intrusion on my own needs. I have also reestablished contact with the AVA, and am already working to defeat legislation which would rob asbestos victims of their right to due legal process. I am writing letters to the editor, contacting media, and generally working to keep the issue of asbestos from being eclipsed from the minds of the public.

There are probably many of you reading this right now who are thinking you really should become more involved in DES Action, BUT...

I want to conclude with a line from a James Taylor song that goes, "You can run but you cannot hide"—how true.

Award for DES Action

The California Trial Lawyers' Association presented their "Consumer Advocate of the Year" award to DES Action at their annual conference in La Jolla, CA, in November.

The handsome plaque notes that the award is "in recognition of their outstanding and tireless efforts aimed at informing the public about DES exposure."

DES Action USA

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