

DES ACTION VOICE

a focus on DIETHYLSTILBESTROL: a national issue

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Officers DES ACTION, National
President: Fran Fishbane
Vice President: Nancy Adess
Treasurer: Pat Cody
Secretary: Libby Saks

Editor: Susan White

Editorial Staff:

Nancy Adess, Kathe Balter,
Fay Cohen, Fran Fishbane,
Andrea Gielen, Evelyn Goldberg,
Marianne Guiffra, Libby Saks,
Carol Simpson

Regional Offices:

DES Action / Massachusetts
P.O. Box 126
Stoughton, Mass. 02070

DES Action / New York
L.I. Jewish Hillside Medical
Center
New Hyde Park, N.Y. 11040

DES Action / Northern California
Womens Building
3543 18th St.
San Francisco, Ca. 94110

DES Action / Oregon
P.O. Box 12092
Portland, Oregon 97212

DES Action / Pennsylvania
Kathe Balter
1812 Pine St.
Phila., Pa. 19104

DES Action / Southern California
P.O. Box 1695
Santa Monica, Ca. 90405

DES Action / Washington
P.O. Box 5311
Rockville, Md. 20851

DES Action / Michigan
P.O. Box 66
East Lansing, Michigan 48823

EDITORIAL

DES DAUGHTERS AND THE PILL

There has been much discussion about whether DES daughters should take "the Pill" for birth control. We have been part of many of these discussions, and we would like to stress our position based on reading the medical literature and talking with medical experts.

DES daughters have all been exposed to a powerful synthetic estrogen: DES. This exposure has caused many daughters to have adenosis, others to have cervical collars or hoods, and others to have the worst effect of estrogen: cancer.

Scientific research has firmly established a relationship between estrogen and cancer. Birth control pills also contain estrogen. Some scientists now think that the way estrogen is related to cancer is that estrogen stimulates a pre-cancerous site to grow cancerous cells. In other words, estrogen may induce cancer to grow in already sensitive cells.

Many private physicians have advised DES daughters not to worry about taking birth control pills. They say, in effect, "We have no proof that taking birth control pills will be harmful," and they imply that those who advise against the use of birth control pills are not basing their opinions on scientific evidence.

We look at this issue from another view: we have no proof that taking the pill is safe. There is no scientific evidence that it is safe. Further, no long term studies have been done on DES daughters and pill use.

A number of prestigious groups and well-respected researchers in the medical field support the idea that DES daughters not use birth control pills. Here is a sample of quotations:

- Former HEW Secretary Joseph Califano: In a press release on DES, the Secretary called it "prudent" for all DES mothers or daughters "to avoid any further use of DES or other estrogens because the carcinogenic effects may be cumulative." (emphasis added)
- The Federal DES Task Force of the Department of HEW: "In view of the lack of information on long-term effects of estrogens in these women (DES daughters) the committee felt that *oral contraceptives and other estrogens should be avoided*. The use of estrogens requires careful consideration by the patient and her physician of alternatives." (emphasis added)
- A World Health Organization Scientific Group: "At least 70% of women exposed in utero to diethylstilbestrol have vaginal and cervical adenosis. Findings of squamous metaplasia, dysplasia and carcinoma *in situ* on the margins of the areas of adenosis have raised anxieties about the potential for malignant squamous cell carcinomas in these women...Combination oral contraceptives may lead to increased squamous metaplastic activity, and therefore probably should not be used by women with cervical or vaginal adenosis....It is inadvisable to prescribe steroid contraceptives for women with vaginal adenosis."
- Furthermore, a recent medical journal article which studied the effects of DES on mice concluded that the results from these studies "call attention to the possible risk of estrogen growth stimulating effect on the DES-induced adenosis and indicate the need to avoid estrogen exposure, including estrogen-containing oral contraceptives, by such individuals."

In our view, the preponderance of evidence is against DES daughters using birth control pills that contain estrogen (almost all birth control pills have estrogen). We would like to wait until the scientific community proves them safe before taking any more chances.

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DES ACTION

Groups in Action

Local Updates

The following are up-dates of the latest activities of local DES ACTION Groups. As you can see, their important work continues to include educating, organizing, and legislative lobbying.

SAN FRANCISCO: Currently, DES ACTION is seeking funds for an audio-visual project which will include a training film for physicians and nurse practitioners, a slide-tape show for nurses and other health workers, and a slide tape show for the public. The group has made a number of presentations to professionals and the public, and has completed a manual on "How to do a Public and Professional Education Project on DES." (Write to San Francisco for more information.) In addition, San Francisco coordinated efforts with DES ACTION Washington in order to fill requests for information generated at the DES ACTION exhibit at the Annual Convention of the American College Health Association.

SACRAMENTO: This newly formed group is coordinating work in DES legislation to be introduced when the legislature reconvenes this autumn.

OREGON: DES ACTION, in coordination with the Oregon Comprehensive Cancer Project, has prepared a "Dear Doctor" letter to be sent to the 4,000 physicians in Oregon. They are being asked if they screen DES patients and if they would be interested in training for DES management. The group is seeking office space, and is planning a fund-raising party for September. A 3M copier was donated to the group. Also in the fall, a support group for DES-exposed will be formed. NOTE: The last newsletter incorrectly reported that the State Legislature will *provide* help to the DES-exposed. Actually, the legislature only *encourages* clinics, agencies, etc. to provide screening, follow-up care and education for the DES-exposed.

MASSACHUSETTS: In the fall, DES ACTION hopes to establish local groups to help provide support and people power for the Boston Project. In terms of the proposed DES legislation, the group feels it is experiencing too much apathy regarding its passage. Currently, the proposed bill is being reworked and resubmitted in hopes that it will then be looked upon more favorably. NOTE: DES ACTION's new mailing address is: P.O. Box 126, Stoughton, MA 02072. Phone: 617-828-7461.

NEW YORK: Heavy media coverage, which generated record numbers of requests, has continued. The group is cooperating with research doctors who are involved in a project that explores DES/Mental Health. DES ACTION was very involved with the DES trial and demonstrated outside the courtroom to show support and solidarity for Ms. Bichler. The N.Y. DES Clinics are beginning to function and the group is available to provide peer counseling. N.Y. is actively seeking funds to support National.

Washington: see p.6

DES and Litigation

First DES Lawsuit Won

Joyce Bichler won the first legal victory against DES. The jury in the N.Y. State Supreme Court in the Bronx decided that Ms. Bichler's cancer was the result of her mother's use of DES, and that Eli Lilly & Company owed the victim \$500,000.

In this case, it was never proven that Lilly manufactured the DES that Joyce's mother ingested during pregnancy. Her lawyer, Leonard Finz based the case on an untested legal premise of joint

liability. All of the DES manufacturers had the responsibility to adequately test DES. The Lilly Company was the target of the suit since it was the major and early producer of DES.

The jury had to consider 7 key questions:

- Was DES safe for miscarriage treatment in 1953 (the year Ms. Bichler's mother was given DES for 2-3 weeks)?
- In 1953, should a reasonably prudent company have foreseen that DES might cause cancer in the offspring of pregnant women who took it?
- Did DES cause Joyce Bichler's vaginal and cervical cancer?
- Foreseeing that DES might cause cancer in the offspring of pregnant women who took it, would a prudent drug manufacturer test it on pregnant mice before marketing it?
- If DES had been tested on pregnant mice, would the tests have shown that DES caused cancer in their offspring?
- Would a prudent manufacturer have marketed DES for miscarriage purposes in 1953 had it known that it caused cancer in the offspring of pregnant mice?
- Did the defendant, Eli Lilly, and the other drug manufacturers act in concert with each other in the testing and marketing of DES for miscarriage purposes?

After the jury reached its verdict, it was reported in the N.Y. Times, 7/17/79, that Fran Fishbane, president of DES ACTION, National, said, "If the pharmaceutical companies had established a fund for the DES-exposed when they discovered the link to cancer (in 1971), they would not now have to worry about the flood of lawsuits that are due to come. I expect they will be swamped."

A Personal View . . .

As the first DES daughter in this country to be successful in a lawsuit against the pharmaceutical companies, I'd like to share a little of the experience with others who may be interested in pursuing litigation themselves. But first, I'd like to thank all those who gave me their encouragement and support during the grueling 2 months of the trial. I had contact with DES ACTION members from N.Y. to San Francisco. It was this type of personal contact and support that kept me going when I thought I could not go back into that courtroom for another day.

I believe my victory was not only important for me but for all DES daughters. For the first time we have established in a court of law that DES causes cancer and that the drug companies should have *foreseen* that it was going to cause cancer in the offspring of women who took the drug. We also showed that all pharmaceutical companies are responsible for what happened even though we could not prove who manufactured the DES my mother took. I suspect that because of this victory many DES daughters will now be able to get their cases into court and many will now come forward to bring action against the pharmaceutical companies who brought this tragedy upon us.

But before people start 'counting their money' I'd like you to know what litigation involves. For one thing I had to wait 7 years from the time I contacted my attorneys to the time we reached the courtroom. During this time there were many depositions and court ordered medical exams. It was very frightening to be questioned by a room full of hostile lawyers. It was also upsetting to have to put my parents through this ordeal. I knew that it was something that I wanted to pursue but found it difficult to watch them relive the events of my illness all over again. They, too, had to take the witness stand and be cross examined about events that took place in their lives so many years ago. I was lucky to have them back me up 100% in my fight against the drug companies.

The daily emotional ups and downs of the trial were more intense than I had imagined. I was spurred on by rage and anger

over what had happened to me but over the 8 weeks of the trial there were times when I almost didn't have the energy to go on. I also never thought I would have to reveal as much about my personal life as I had to when I took the witness stand. No aspect of your life is private — all must be revealed. The same was true for my husband for he, too, had to discuss how my surgery had affected our lives.

Going through the trial was the most difficult thing I have done since my surgery. My whole life for those long 8 weeks revolved around the events that took place in that courtroom. It is not something to be taken lightly but something you must feel is the right thing to do. For me, there was no question that it was the right thing to do and, of course, now the satisfaction of the victory is indescribable. If you are interested in pursuing legal action, I'd advise that you first discuss this with your family for they, too, will be involved. Secondly, consult an attorney who is knowledgeable about the DES issue. There are attorneys across the country handling cases and your local DES ACTION chapter or DES ACTION National could probably hook you up with attorneys in your area who are handling other DES cases. Most important of all is to seek legal advice as quickly as possible. The statute of limitations varies from state to state but in almost all cases it is very restrictive for the DES plaintiff and could prevent you from bringing legal action entirely if you wait for any length of time.

Going to court is hard emotionally, mentally and oftentimes physically, too, but unless we start fighting back we are giving the pharmaceutical companies the 'O.K.' to continue putting inadequately tested drugs on the market. We've got to let them know that what they did was wrong, that they must take responsibility for what they have done to us, and that we're not going to let this happen again!

If anyone would like more information, please feel free to contact me through DES ACTION/San Francisco.

Joyce Bichler

Editor's Note — See DES Information Service in Loose Ends.

Special Feature THE CO² LASER

Burton A. Krumholz, Associate Chairman
Dept. Obstetrics and Gynecology

The carbon dioxide Laser is a surgical instrument. A highly complex mechanism using high electrical energy converts the molecules of CO² into a powerful beam of infrared light — *The Light Knife*. This beam of invisible light has no relationship whatsoever to x-ray or other types of radioactive beams. It is nothing more than a powerful beam of light which is carefully focused, although it is invisible. This beam is so small and so precise that it is generally controlled by an operating microscope (microsurgery). The beam cuts by vaporization of the water of the tissue in its pathway. The width of the incision is approximately the same as a fine line of a pen. The depth of the incision depends upon the electrical power producing the beam, as well as the time the beam is applied. For this reason, under direct vision abnormal areas of surface tissue can be precisely removed.

This instrument is not used for cancer surgery. It can be used for the removal of surface malignant changes before a real cancer is present, as well as for other precancerous conditions. Over 95% of the tissue changes (adenosis) which are present in DES-exposed women are totally benign and require no other treatment other than observation. In the remaining 5% or less in whom biopsy of the tissue reveals potential premalignant changes, removal of this tissue may be indicated. Because this tissue can be removed from widespread critical areas of the

cervix and vagina with little or no anesthesia and without the need for hospitalization, it is preferred to the usual surgical procedures which do require hospital admission. In addition, following Laser surgery, there is very little scarring as compared with conventional surgery. This latter advantage also holds in comparison to freezing (cryocautery) or burning (thermocautery) of the tissue.

The use of this method is relatively new and continues to be investigated. In general, it is a fair statement to make that it should only be carried out by someone who is expert in colposcopy.

We look forward to continued use of this method.

DES and Government FDA UPDATE — DES IN ANIMAL FEED

On June 20, 1979, FDA Commissioner Donald Kennedy retired, and one of his last announcements that day was that DES would be banned for use in sheep and cattle feed.

The ban was a culmination of hearings which began in November 1976 and of the resultant administrative judgment by Judge Daniel Davidson (September 1978) that pointed out the harmful effects of DES. Kennedy considered the following issues in his decision:

1. his conclusion that DES causes cancer and that it was *not* shown in the hearings that there is an amount below which it does *not* cause cancer.
2. residues of DES occur in food from DES-treated animals.
3. the law does not authorize FDA to consider the economic benefits of drugs such as DES and, in any event, those opposing the ban have not demonstrated that the ban would have a negative economic and/or environmental impact.

The FDA previously had tried to remove DES from animal feed in August 1972 and to ban DES as an animal implant in April 1973, but the U.S. Court of Appeals, District of Columbia, overturned these attempts due to the fact that hearings had not been conducted. New proceedings began in January 1976 and four firms from the cattle and drug industries requested hearings, those that consequently resulted in the ban.

Kennedy ruled that all manufacture and shipment of DES as an animal drug be ceased on July 13, 1979 and that its use as such be stopped on July 20, 1979. But because petitions against the ban on use were received by more than eighty feed manufacturers, livestock producers and producers groups (such as the National Cattleman's Association), the ban was postponed for two weeks. After consideration of the petitions, a further extension until November 1, 1979 was imposed. This means that DES is still being used (although no longer manufactured) as feed premix, food treatment and implants.

The FDA denied two drug manufacturers, Hess and Clark and Vineland Labs, petitions for postponement of the manufacture ban, but the companies brought their cases to the U.S. Court of Appeals (D.C.) The court has not yet accepted their appeals; however, should they do so, the production/shipping ban could be lifted. It may be months, or longer, before the process is complete.

Other estrogenic compounds or drugs with estrogenic activity are being used, of course, and little is known about their possible specific carcinogenic properties because residues in meat may or may not exist. Examples of these other drugs are Synovex H (estradiol benzoate with progesterone), and Synovex S (estradiol benzoate with testosterone) which are, chemically, only one "functional group" (structural difference) from a natural

estrogen, and are very close to DES. Ralgro (zeranol) is not estrogenic but has estrogenic activity. In fact, hormones in not inconsiderable amounts occur naturally in untreated animal meats. These issues are raised to demonstrate the need for more scientific research into food additives.

One major step for elimination of DES from our food, then, was finally made.

(The information for this article was kindly contributed by Marianne Guiffra, FDA)

DES AND THE SCIENCE FOREFRONT

FERTILITY OF THE DIETHYLSTILBESTROL-EXPOSED OFFSPRING, Siegler, AM, Wang, CF, and Friberg, J. *Fertility and Sterility*, 31(6):601-7, June, 1979.

The authors review the available research and literature on fertility among DES sons and daughters.

The structural abnormalities seen in the reproductive tracts of DES daughters such as cockscomb, adenosis, cervical collar, etc. still have no known relationship to infertility, but the authors feel that some extensive cases may experience poor sperm migration. One article they reviewed included data on 66 DES-exposed women. Of the 31 whose mothers had used DES in the first trimester of pregnancy, 71% had abnormal hysterosalpingograms (x-rays of the uterus using dye). However, the significance of the abnormalities in relation to child-bearing is yet unknown.

Another study reported in this article describes five (of nine) DES daughters who experienced "incompetent cervix" (a cervix which gives way under the pressure of pregnancy). Four were treated successfully by surgery and bore live children.

Bibbo and colleagues (as well as other investigators) found a significantly higher number of menstrual complaints among DES daughters than unexposed females of the same ages. DES, however, seems to have no effect on age at onset of menstruation (menarche) nor on regularity of cycles.

Although no increase in genital cancers has been shown, other benign abnormalities are found more often among DES sons than among unexposed males, according to several studies. These include cysts, undersized penises or testes and varicoceles. One group of researchers reported more problems with urination and symptoms or urethral stenosis (narrowing of the tubes through which we urinate) in DES sons as compared to a control group. Sperm counts were more often low, and luteinizing hormone levels (hormones as found in the egg) were higher in DES sons.

Information on actual infertility in DES-exposed offspring is still anecdotal. Although fewer DES women in several studies have borne children, data are not conclusive.

Management of DES sons or daughters with infertility complaints is recommended by the authors to be basically the same as for any person with the complaint of infertility. The Pill or other estrogens "should be avoided."

RISK FACTORS FOR CANCER OF THE TESTIS IN YOUNG MEN, Henderson, BE, Benton, B, Jing, J, Yu, MC and Pike, MC. *International Journal of Cancer* 23: 598-602, 1979.

An individually matched case-control study of testis cancer in 131 men under 40 years of age was conducted by the authors to investigate antecedent risk factors (including events during prenatal life) that may have caused their cancer in later life. Ten patients were born with an undescended testis compared to only two in the control group (this being highly significant statistically). Two new risk factors were uncovered: six patient's mothers had received hormones during their pregnancies compared to only

one mother in the control group, and eight versus two mothers had reported excessive nausea as a complication during their pregnancies. The authors present a hypothesis for their conclusion: that a major risk factor for testis cancer is a relative excess of certain hormones (in particular estrogen) at the time when the fetus is developing testes.

DES Exposure Found to Affect Pregnancy

As the Voice went to press, a study from Baylor Medical School in Houston, Texas was released. Young women, whose mothers took DES, were studied during their pregnancies. Using hysterosalpinography, the Baylor team examined 267 women and discovered abnormalities in 69 percent of them. This may indicate that there may be increased difficulty in carrying a pregnancy to term for the women with these structural abnormalities in their reproductive tracts.

Dr. Raymond Kaufman, who heads the DES program at Baylor will contribute an article on this topic for the next Voice.

Editor's note: The DES Task Force Report recommends against routine hysterosalpinography.

BE AN ENLIGHTENED MEDICAL CONSUMER

DEAR DOCTOR...

We are grateful to Dr. Arthur Herbst, Chairman, Department of Obstetrics and Gynecology at the University of Chicago for responding to these questions:

1. I am a 24 year old DES daughter suffering from endometriosis. Is my condition related to DES? Can you explain endometriosis? What is the best treatment for this?

There is no evidence that endometriosis is related to DES at the present time. It is a condition where benign tissue that looks like the inner lining of the uterus grows outside of the uterus. It may not require any treatment, although occasionally the condition is associated with infertility and pain.

2. My doctor said that my adenosis is disappearing. What does this mean? Am I still at risk for cancer? Must I continue to have DES exams?

It is encouraging that your adenosis is disappearing. However, it is wise for you to continue to have regular checkups.

3. Now that I am 30 years old my doctor said I no longer have anything to worry about. Do I still need DES check-ups?

Even though the maximum risk of clear cell adenocarcinoma appears to be in those at about age 19, cases in older women do occur and you should continue to have regular checkups.

Editor's note: Continue to send your questions to the Voice.

Obtaining Military Records

All military records are not obtainable in the same way. For records pertaining to treatment in the last five years, contact the military medical facility where the person was treated. If the treatment occurred more than five years ago, those who were active duty members should send requests to:

National Personnel Records Center
Military Records
3700 Page Blvd.
St. Louis, MO. 63132

Dependents and others must write to:

National Personnel Records Center
Civilian Personnel Records
111 Winnebago St.
St. Louis, MO. 63118

Each request should include the following information:

- A. Name of place where treatment was obtained.
- B. Date(s) of treatment(s) (at least, give year)
- C. Sponsor's name, rank, and SSN or service number at that time.
- D. Authorization for release of information; for adults, signed by the person who received treatment; for minors, signed by parent or guardian; for deceased persons, signed by next of kin.
- E. Type of record requested: inpatient, outpatient, or both.
- F. Name and address of medical facility or physician to whom copies are to be sent, if so desired.

Medical records are forwarded from each medical facility to the National Personnel Records Centers after five years for retention and eventual destruction. Records for active duty members are destroyed 50 years after last treatment; for non-military beneficiaries, records are kept 25 years following last treatment.

Few followup studies have been done on DES exposed military mothers, sons, and daughters (Lurain and Gallup reported colposcopic findings from 53 DES daughters examined at the Naval Research Medical Center, Portsmouth, VA. in the *Southern Medical Journal* in July, 1978). The total number of exposed is unknown. The military will treat all eligible beneficiaries either in military facilities, if the capacity exists, or under the auspices of CHAMPUS. Sons and daughters past dependent age, however, are not eligible for care in military hospitals.

If, after following these recommendations, you still encounter difficulty in obtaining military medical records, please contact Dolores Wallgren, DES ACTION, Washington.

DES Daughters -- Beware of Mammography

Attention, DES daughters! Many DES daughters have reported to us that they have "cystic" or lumpy breasts more frequently than their non-DES sisters. We are now beginning to hear that some doctors are recommending mammography in order to establish a "baseline" reading of the lumps and whether they might be malignant.

Mammography involves taking x-rays of the breast to see the size and shape of any lumps or masses. The use of mammography has aroused controversy in recent years because many scientists and doctors believe that x-rays of the breast can actually *add* to a woman's risk of breast cancer. Radiation can be cancer-causing (carcinogenic), and carcinogenic agents, it is thought, can be stored for many years in body tissues. Therefore, exposing a person to radiation can increase that person's risk of cancer many years later.

We asked members of our Medical Advisory Board whether DES daughters should have a mammogram if they have breast lumps. They answered that mammography should *not* be used any more frequently on DES daughters than on other women.

DES daughters should be aware of the National Cancer Institute's guidelines on mammography. The guidelines state that women under 35 should not have mammography for routine screening. Women age 35 to 49 should only have mammography if there is a history of breast cancer in the mother or a sister or if

the woman has already had breast cancer. Over age 50, women may wish to have routine mammograms because the risks of developing cancer many years later are thought to be less than the benefits of discovering cancer at that age.

Although there are mammography machines that are said to emit very low doses of radiation, the machines are difficult to control and one cannot be sure about the exact amount of radiation being emitted.

What can you do? You should seek an expert in your area who is highly skilled at breast examinations without mammography. Most university medical centers will have a breast specialist. Contact the university ob/gyn department or a Planned Parenthood for a referral.

A breast specialist can talk with you and show you what she or he is feeling in your breast. She/he can also show you how to do a careful breast examination on yourself. Also, the American Cancer Society has a free pamphlet called "How to Examine Your Breasts", available from the Cancer Society in your area.

If you are concerned about lumps in your breasts, the following facts might help:

- most women have some lumpiness in their breasts; some have more, some less.
- if there are many lumps, it is probably not cancer
- if the lumps come and go during your menstrual cycle, it is probably not cancer.
- if the lump is constant, but does not change and is not a well-defined mass but "slips away" at the edges, it is probably not cancer.
- a lump that does not start as cancer does not become cancer.
- periods of stress may cause changes in the lumpiness of your breasts.
- the average woman's risk of breast cancer is 7% for her whole lifetime.
- for women under 30, there are more deaths due to accidents, flu and pneumonia than to breast cancer.

If a lump or mass in your breast is considered suspicious for cancer, a biopsy can be done to examine a sample of the tissue under a microscope. The biopsy can be done on an outpatient basis in many cases.

Remember, if you are worried about lumps in your breasts, get examinations as often as you desire by a specialist in breast examination without mammography. And learn how to examine your own breasts, and do so after your period every month.

Editor's note: DES mothers should also be aware of N.C.I.'s guidelines and follow their recommendations.

LOOSE ENDS

Boston Litigation

Class Action status, a first in the country, has been granted to a Massachusetts DES lawsuit. All 5 of these criteria must be met to qualify for the suit.

1. exposed to DES *in utero*.
2. exposure occurred in Mass.
3. born in Mass.
4. domiciled in Mass. when they receive notice of this action and
5. have not developed uterine or vaginal cancer.

Any woman believing herself to qualify should contact the plaintiff's attorney,

Rosenberg, Baker and Fine
133 Mt. Auburn Street
Cambridge, Mass. 02138

Network offers DES Litigation Information Service

Joyce Bichler will chair the National Women's Health Network's DES Information Service. She will share her knowledge about DES lawsuits. Currently, a number of DES court cases are pending and attorneys in Detroit, Boston and Chicago are bringing class action suits. Anyone seeking to obtain information about a DES lawsuit may write: DES Litigation Information Service, National Women's Health Network, 2025 "I" Street NW, Suite 105 Washington, D.C. 20006.

Chicago Suit- \$800,00 in damages was awarded to Anne Needham. Unlike the Bichler case, the precise drug source was documented and White Laboratories was found to have been negligent in its testing and marketing of DES.

The Voice apologizes for the delay in the publication of this issue. Our volunteer staff was occupied full-time responding to the overwhelming numbers of inquiries from the *Parade* article.



DES ACTION/Washington participated in the 57th annual meeting of the American College Health Association, held at the Shoreham Hotel in Washington, D.C. The booth was staffed by Phylis Savage, Lillian Tompkins, Shirley Schumacher and Dolores Wallgren. Our literature was eagerly sought after by the nurses, doctors and health educators attending. The 1980 ACHA 58th annual meeting will be held in San Diego. DES ACTION/San Francisco plans to participate.

Male Study- The Family Studies Laboratory at Boston University Medical Center is planning a limited study of DES sons. Men, 21 or older, living in the Boston area can call or write for further information:

Richard Pillard, M.D.
Family Studies Lab
85 East Newton St.
Boston, MA 02118
(617) 247-5485

Letters to the Editor

Dear DES ACTION,

It was very good to speak with you on Monday. I greatly appreciate the letter you sent me about my article. (Editor's Note: Ms. Bretton's article appeared in *Newsday*.)

My article really only touches on the surface of how I felt during the — I'm ashamed to admit — fourteen months it took me to come to grips with being DES-exposed and to finally go to Dr. K for a colposcopy. I was lucky — I only have a very small patch of adenosis on the upper wall of the vagina and only need to see him once a year. However, there is no way I can describe the fear I felt while waiting to see him. The room was literally filled with our fears — you could almost see it and smell it. Others there weren't as lucky as I — they sat on the sofas crying, their mothers patting their arms helplessly. It hit me then more than it ever had before, how devastating the destruction from DES really is. At one point before I had the exam, I tried to convince my husband to promise to divorce me if I ever had to have a vaginectomy or anything. Thank God, he was nothing but supportive and helpful to me as I tried to work out my feelings and he didn't listen to my asinine suggestions. At one point I even decided I didn't want to have sex any more — or, if I did, I refused to enjoy it as I used to. I had decided that sooner or later that gift would be taken away from me via surgery, and I had better get used to it.

As terrible as it was before the exam, that's how good it was after. Things popped into place as quickly as they had fallen apart. I began going back to college at twenty-seven, I began writing seriously. I began taking better care of my physical self: running, swimming, biking at least three or four times a week. All of this as a direct result of the DES scare. I decided that for as long as I'm going to be around, I'm going to do as much for and with myself as humanly possible. In some strange way I am a stronger and happier person now than I was before.

At the beginning the words "DES" and "Cancer" were on my mind literally twenty-four hours a day. I couldn't believe I would ever forget about them even momentarily. Now weeks on end go by without those old nightmares. I haven't forgotten, but I have gone on living.

What you are doing for people like myself is incalculable. In fact, if I hadn't spoken to you back in 1977, I probably would still be trying to scare up the nerve to make an appointment with Dr. K! If there is anything that I can do, please tell me. I would be more than glad to help however I can.

Thanks again,
Barbara Bretton
North Babylon, N.Y.

Dear Friends in DES ACTION,

I am a DES mother with two DES daughters. We have just learned that our 21 year old son is sterile. The sperm count in several tests was negative — zero.

After a 5 year search, I have finally been able to document that I was given DES. All the information on the dosage and time were dictated into my medical history on my charts at the hospital. Tell everyone not to give up and to demand to see the records for themselves. They told me over the telephone that they had searched my histories and had found no evidence of my being given DES. (I told them to look for diethylstilbestrol.) I insisted on looking for myself, and armed with your pamphlet with all the names under which it was given, I found it. Thanks to the Freedom of Information Act these records are now available to everyone.

You have no idea how many dead end trails I have followed trying to get this documented — through doctors who are dead and their files destroyed, pharmacies that went out of business long ago, even searching through 20-25 year old cancelled checks trying to find a clue. I just wouldn't believe that there wasn't some way to find documentation. I was re-reading all your literature the other day and you mentioned checking hospital charts — and finally SUCCESS.

To me, the effects of DES are as devastating as the thalidamide babies. Maybe more so — it was given for so long and all the facts are not in yet.

There should be a cry of outrage sweeping across our land for all to hear when young women develop cancer and young men are sterile.

The Food and Drug Administration was so proud of itself for keeping thalidamide out of the United States. Where were they when DES was developed and prescribed for women during pregnancy?

Thank you for all your information and moral support through the years. Don't let them minimize or try to white wash the effects of DES.

Sincerely,
DES mother
Amarillo, Texas

P.S. What about the DES fathers? My beloved husband is as grief-stricken about all this as I am.

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References:

- Califano's press conference: October 4, 1978
- Federal DES Task Force, Summary Report, page 40.
- World Health Organization Scientific Group, "Steroid Contraception and the Risk of Neoplasia," December 5-9, 1977. pp.38-39, 48.
- Kalland, T. et. al., "Localization of 3H-Estradiol-17B in Diethylstilbestrol-Induced Adenosis," *Obstetrics and Gynecology*, Vol. 51-No.4, April 1978.

Editor's Note: A preview of *The "Ms." Medical Guide to a Woman's Health*, which appeared in Ms. magazine 9/79, warned that exposure to DES should serve as a strong contraindication of the pill.

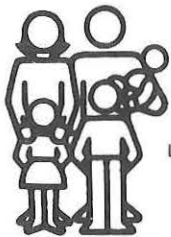
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Random Notes from Fran Fishbane..

For the first DES screening exam, it is vital to choose a *compassionate* and skilled physician. Honest and open discussion between you and your youngster can ease your mutual anxiety.

There are other sensitive issues to consider. Occasionally a very young teenager may be sexually active. She may fear that the doctor will recognize this and betray her situation to her parents. Confidentiality between patient and doctor must be stressed.

Our mail indicates overtreatment in many cases. Should your gynecologist advise you that surgery is required (no matter how simple the procedure) **INSIST** upon a consultation with another physician.



DES ACTION

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