DES ACTION VOICE

a focus on DIETHYLSTILBESTROL: a national issue

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From the National Board . . .

DES ACTION and Litigation

At the November Board meeting a major topic of discussion was the subject of lawsuits concerning DES. Since Joyce Bichler's victory in the court last summer, DES ACTION groups throughout the country have received many requests for help in filing suits for damages due to DES exposure. While we will continue to respond to these requests for help, the Board resolved that the following policy statement be publicly issued regarding our position on litigation:

> "DES ACTION IS A GROUP DEDICATED TO IDENTIFYING DES EXPOSED PERSONS, ASSISTING THEM IN FINDING APPROPRIATE CARE, AND PROVIDING SUCH COUNSELING AND REFERRALS AS ARE AVAILABLE. DES ACTION NATIONAL AND ITS LOCAL CHAPTERS NEITHER DISCOURAGE NOR ENCOURAGE LITIGATION ON BEHALF OF DES EXPOSED INDIVIDUALS."

We felt that it was important to develop this statement to reaffirm the aims of DES ACTION; our commitment to the identification and education of those exposed to DES. In addition, we recognize the need to educate both health professionals and consumers about this drug and its effects. We will continue to direct our energies towards these goals.

DES Groups in Action . . .

Local Updates

No Energy Shortage Here!

Since we last reported on DES ACTION Groups' activities, our ranks have expanded to include new groups in Connecticut, New Jersey, Michigan, and most recently, Illinois. With our continued work, the DES issue is becoming recognized by more of those affected as well as the health care profession.

CONNECTICUT: The DES ACTION Benefit was held in late January at the Hartford YWCA. Featured were members of the group sharing various aspects of their experiences as DES daughters, and Dr. Michael Baggish, Director of Obstetrics and Gynecology at Mount Sinai Hospital, Hartford. The benefit was a success and helped to increase the visibility of DES ACTION Connecticut.

MICHIGAN: DES ACTION has launched a one-year CETA project sponsored by the Ingham County Women's Commission in Lansing. The "DES Information Alert" will distribute educational materials and give presentations to a broad spectrum of community and health care groups. A detailed listing of doctors who can treat DES exposed children and mothers is being compiled. Meanwhile, the group continues its legislative work and has also recently started a new Detroit group.

ILLINOIS: The newest DES ACTION Group is in the process of forming in the Metropolitan Chicago area. The group is interested in recruiting new members and those interested should call Suzanne Saposnik at the Loop YWCA, 372-6600.

A group of DES mothers and daughters from the group met with Stephanie Henderson, the newly appointed Director of the State Health Department's DES program.

PENNSYLVANIA: DES ACTION is in the process of planning a spring conference at the University of Pennsylvania on DES. The group has also been in touch with the State Health Department.

OREGON: DES ACTION is hard at work helping to implement its legislation, which was passed last spring. Peg Beckwith also reports that DES ACTION Groups may be starting in Eugene, OR, Vancouver, BC and Clarkston, WA. Others interested and living in those areas should contact peg.

MASSACHUSETTS: DES ACTION has moved to suburban Stoughton and is in the process of gathering new members. New energies are especially needed to help work on a survey of Boston DES Doctors and on the Massachusetts legislation, (the bill died in the last hours of the 1979 session, and will hopefully be resurrected this year.)

WASHINGTON, D.C.: DES ACTION has continued its usual active level of publicity about the issue, with TV appearances, booths at area college health fairs, and public meetings.

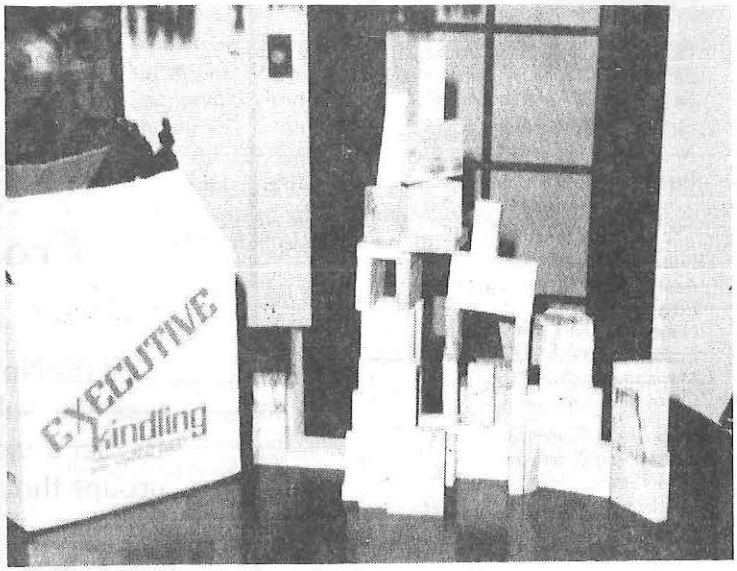
CALIFORNIA: By press time, the California bill should be introduced, and DES ACTION will be assisting in the testimony surrounding its debate. The group also plans to attend the 11th National Conference on Women and the Law, Feb. 28 - Mar. 2, 1980.

New DES ACTION/Detroit, P.O. Box 8663, Detroit 48224. New phone (313) 371-8696.

NEW YORK: The group's input has been utilized in the actual operation of the Screening Center's education and counseling programs. Plans are in the works to jointly conduct rap groups with the center. A press conference, to be held by Long Island Jewish Hospital to further publicize the Center and DES ACTION are also planned.

They are working in conjunction with a doctoral student in writing a DES questionnaire to examine the psychological coping patterns of DES mothers. It is hoped that the results of this project can be used to pinpoint areas of future study.

NEW JERSEY: DES ACTION is proud to report their state DES Bill was passed unanimously and is awaiting the governor's signature. A successful public seminar on the then pending legislation and the public's role was held. N.J. is organizing a peer support group network. They will be participating in a local Health Fair.



A successful fundraising activity by DES ACTION/Oregon. This wood, used for creative activities, was sold to nursery schools.

Personal Views

DES Daughters and Their Mothers: Bridging the Gap

Lately, it seems, the special relationship between mothers and daughters has come under close scrutiny by a number of media. Books like *MY MOTHER, MY SELF* (Nancy Friday) and *MOTHERS AND DAUGHTERS* (Signe Hammer) have helped to spread the examination of the forces that bind and divide women from and to each other. And the wave is spreading — suddenly I find my friends analyzing their relationship with mom instead of simply complaining about it.

It seems that DES daughters and mothers have an extra, complex burden in resolving some of their problems with each other. I am a DES daughter, and have had to shoulder some of this burden as my mother and I have held our breath at colposcopy time every six months. We have never said so, but I am sure that when the results are in we both breathe a quiet sigh of relief.

As a member of DES ACTION Michigan, I talk to women from all over my state about personal as well as political concerns. That phone call that takes me away from the dinner table may be a mother whose daughter is about to undergo surgery, or a woman trying to confirm that she's DES exposed and needs help in trying to deal with asking her mother.

The usual maternal reaction is guilt: "What have I done to my daughter? Why did I take that drug? Why did I trust my doctor?" and the mother who doesn't express guilt immediately is usually quick to deny it. This process of denying feelings can lead to closing other doors of communication — especially with the affected child — and can be very destructive, perhaps more so than the effects of DES.

An example of this is the mother I met at a social group's brown bag luncheon at which my group spoke. She knew her daughter

was DES exposed but refused to tell her on the grounds that the daughter was "high strung" and, at the time, pregnant. She instead told their mutual gynecologist-obstetrician, who was caring for the daughter during her pregnancy. Many nights since I met this woman, I have laid awake wondering how that daughter would feel if she knew her mother was withholding vital health information.

I do not blame or hold my mother responsible in any way for my DES exposure. I constantly encourage her not to feel guilty. But if she didn't tell me something as vital as the simple fact of my exposure, then I might feel that she was not acting in my best interest.

The 'blame-the-mother' undercurrents that I sense sometimes in articles about DES aggravate me for just this reason. They are just like the 'blame-the-victim' myths about rape. The implication is that a woman who had a difficult time maintaining a pregnancy or had diabetes, or spotting, or who was a little bit too old to be carrying a child, or whatever, had no business getting pregnant. That taking a drug like DES was risky, but that the burden of proving it safe fell not on the manufacturer, but on those women and their fetuses — us. It grieves me that mothers feel guilty — but it doesn't surprise me.

So I think there are some things, in view of all of the above, that can help us help each other. Telling the truth, of course, and working together to find records of the pregnancy. Always being ready to share and to listen to feelings — for both mother and daughter may need support. Sometimes a rap group which includes other mothers and daughters may help — and if there is not one going in your area, you may want to run a classified ad in your local paper and start one.

DES mothers of exposed sons may be reading this and wondering why there is no reference to their situation. The problem is that I have met few DES sons who were willing to talk about their feelings, and about their relationship to their mothers. Recently, however, a DES son joined our local group, and over lunch shared his feelings about his DES exposure. Finally there was reference made to his mother's feelings, and, more specifically, to her feelings of guilt. I told him how common this was with DES mothers, but immediately realized that all the mothers I had contact with were mothers of daughters — perhaps a DES son has different nuances of communications with his mother (Ed.'s note: an article by a DES son will be in a future Voice issue).

Finally, to my fellow DES children; don't be surprised if you find that it's difficult to persuade your mother not to feel guilty. By working on the issue of DES together new channels of communication must be opened between you, and may strengthen your relationship despite the problem that you share.

Active Participation

by Paula DiStabile,
R.N./Nurse Practitioner

DES ACTION members and supporters have finally seen their hopes become reality as the N.Y. State DES Screening Centers have begun operation. Our center is based within the facilities of Long Island Jewish-Hillside Medical Center and Nassau County Medical Center and will serve the entire Queens-Long Island area. Services include public and professional outreach, counseling and education, medical care for daughters and referral. All DES-exposed persons are free to choose any medical provider, but are encouraged to take advantage of our other services.

A basic philosophy for health care provision directs the practice of all professionals and institutions. Our staff considers women and men of all ages to be whole, acting and interacting human beings. We function to assist clients in attaining their goal of optimum wellness by providing DES related health care. Our clients are active participants in the health care process. This involves hard work for each of us, but results in mutual satisfaction.

Honest communication is essential in this setting. Fears and uncertainties cannot be eliminated unless they are surfaced. The emotional impact of DES exposure needs to be dealt with in whatever manner is appropriate for the individual; both peers and professionals are available. Accurate information about DES exposure can help to reduce much of the anxiety and foster good self care practices. Anatomy, physiology, embryology and examination techniques are not mysteries reserved for professional use only. We share this knowledge with our clients and expect them to use us freely as resource persons.

Many women fear pelvic examination for a variety of reasons. It is also possible to experience pelvic examination as a very positive learning experience. We attempt to provide this by active client participation. Clients are free to learn or review breast self examination, attempt to feel for the uterus beneath the abdomen and observe the colposcopic examination on our television monitor. Where this is not available, a mirror can be used to view the cervix and vagina. The woman is free to create whatever experience is most comfortable for her.

We rely heavily on our clients for feedback concerning the quality of our service. We also depend upon DES ACTION members for suggestions and guidance in planning. Our goal is to identify and meet the needs of all DES exposed persons in our area. We all share a right to high quality health care; we also share equally the responsibility for providing it.

(Editor's note: Patients at the N.Y. Screening Center are benefiting from the staff's TLC and expert knowledge as expressed in the following letter)

Dear Friends,

My wife and I just wanted to say thank you for the thoughtful and more important, the gentle way the folks at the screening center treated our daughter. She is almost nineteen years old and she knew that this was a test that had to be done. The idea of it made her very uptight, and like most young people she had a million reasons why she could not go. We finally set the time for her and even though she was a wreck on the way there, as soon as the screening session had begun she realized that it wasn't that bad.

Your staff treats these young people as adults but still keeps in mind that inside they really are scared. The pre-screening period answers everything that they may be too afraid to ask or just don't think about. The personal interview was the area where she was put at ease the most; personal questions were answered with frankness and the fears she had were explained away. When she was finished she said to my wife that it was a load off her mind.

At a time when no one really seems to care, the screening staff helped our daughter over a tough time by their gentle and concerned attitude. We thank you very much for being there, and would advise anyone who has to take the test not to worry; it's better to be sure now than sorry later.

Very truly yours,
M. Baines

DES Daughters and Their Husbands: Shared Concerns

One aspect of the DES story which requires far greater attention is the role of the DES husband. Although my wife and I frequently discuss the impact of new legislation, consumer education, peer support groups, and standards of medical care, we have never really tackled the question of a mate's responsibilities to his DES affected spouse.

I wonder to what extent other husbands share the same concerns; how well prepared they are to ease their wives' fears, to accept the emotional inevitabilities of DES or to face the semi-annual checkups and the accompanying fear of what the colposcopy may discover.

Do other husbands join their wives in the doctor's office? Are they confronted by the same anxieties, occasional feelings of helplessness, or the sometimes overwhelming inability to truly empathize with their spouses' emotions? Do they know what to say, how to say it, when to say it? How easily can they accept a potentially higher likelihood of physical trauma?

When I entered into my marriage, I was aware of my wife's DES background and her continuing need for medical examination. However, I never really understood the all-pervading effect that the drug would have on our lives, both individually and as a family; how ill-equipped I was (and still am) to deal with it.

Although I and other husbands are always by our wives' sides, I feel that's not enough; we must do more to understand how each of us is involved in similar situations. We must communicate with each other, share our experiences, grow, learn, and provide even more help to our mates and ourselves.

Editor's note: The Voice would like to publish additional personal articles: Share your experiences, questions, and concerns. Send your articles to DES ACTION Voice, L.I.J., New Hyde Park, N.Y. 11040.

SPECIAL FEATURE

DES Sons

Dr. Henry Abrams, Urologist
Long Island Jewish-Hillside Medical Center

Boys who had a prenatal exposure to DES are running a substantial risk of developing infertility, testicular abnormalities, and epididymal cysts.

The mass media, while warning of the DES danger to girls, has neglected to note the danger to males. There are approximately a million males born between 1940 and 1971 who are currently at risk.

A study of 250 DES-exposed adolescent and adult males and an equal number of matched controls reported by Dr. William Gill of Chicago disclosed that 30% of the DES group showed some testicular abnormality, versus 8 percent of controls. Our own studies at LIJ-HMC support these findings.

Benign cysts in the sperm storage duct, the epididymis, were the most common lesion, affecting 19.0 percent of the drug group, and 5.2 percent of the controls. Hypoplastic (small) testes was discovered in 8.3 percent of the DES sons, and in only 1.7 percent of the non-exposed.

Urethral stenosis, urinary tract infections, kidney and bladder pain, penile discharge, and problems in passing urine have been reported in some studies.

Varicoceles, indurated testicular capsules, and cryptorchidism are more common among DES sons, and are documented by all of the literature. Interestingly, the Chicago study showed no difference between DES and control groups' sex hormone levels, frequency of urinary tract infections, or age at puberty, first ejaculation, or first sexual intercourse.

The pathologies of DES are not always immediately apparent. Some, such as the epididymal cysts, may occur and reoccur with time. DES patients should examine themselves for cysts at least once every three months. The boys should begin early to establish the habit. The cysts are painless and can be overlooked.

Pediatricians should pay minute attention to the testicular development of their DES-exposed adolescents. The adolescent should be informed of possible risks by age 15 or 16. The time of the discussion should vary with the maturity of the individual patient. Semen analysis can be deferred until after the age of 18.

Infertility, due to a sperm count below the minimal standard of 20 million per cc, afflicted 20 percent of the Chicago DES group, versus some 5 percent of the controls. An absence of sperm coagulation affected 17 percent of the problem group, versus 5 percent of the normal population.

Cancer is the change which is most feared and most unpredictable. Present studies have not demonstrated carcinogenesis in males exposed to DES in utero. However, two factors which may influence malignancy bear watching. One is the prostatic utricle which is homologous to parts of the female reproductive tract. Such cancers are rare and are not noted until the sixth to eighth decade of life.

Cytologic examinations of prostatic fluid, seminal vesicle secretions, and urine before and after prostatic massage and ejaculation have all been negative for tumor cells.

Two other non-DES related studies have linked an increased risk of testicular cancer in males suffering from cryptorchidism. Sixty-three percent of patients exposed to DES who had small testes had a history of cryptorchidism. This theoretically raises the risk of testicular carcinoma.

Present studies indicate that transplacental effects of DES on human males do occur.

Structural and functional changes which impair fertility may follow. Although no malignancies have been found in males exposed to DES in utero, more time and further study is needed to clarify this question.

DES AND GOVERNMENT

"Government's Responsibility to DES"

by Freeholder Joan Steinacker

Early in this century, Upton Sinclair wanted to change the economic nature of things in America and wrote *"The Jungle,"* about life in the stockyards of Chicago. Instead of the changes in our economic way of life that Sinclair envisioned, a hue and cry throughout the country resulted in the first of our pure food and drug laws.

The Congress recognized the obligations of the government to protect the people against foods and drugs that would have longterm deleterious effects upon the human body. Sinclair, working from a point of view that was not acceptable to the American people did, in fact, influence us to the responsibility of government for protection in an entirely different field.

Over the years, highly restrictive laws have been enacted — all with the objective of protecting the people against dangerous substances. Other movements have been wedded to the overriding theme of health protection through tough laws and law enforcement.

I suppose we are as well protected against troublesome materials as any people on earth. Yet, for thirty years, from 1941 to 1971 our government tolerated diethylstilbestrol — DES. The subject is of special interest to me because I am personally involved. My physician prescribed DES for me and now my daughter does have problems. The watch will go on, and on, year

in and year out.

I am a politician and a public official, part of the system and, as such, I am part of the structure that allowed this to happen to myself, to my daughter and to millions of others. The government failed us, and I believe the government has some obligations to all of us as a result of that failure.

Apologies from the Food and Drug Administration are not enough, Mea Culpas from the scientific communities are not enough. Excuse me's from the drug industry are not enough. There are two things I want from the government in relationship to DES and I am committed to working for both for as long and as hard as it takes.

First, from personal experience, I can tell you that the costs we are now experiencing in my own family to keep my daughter under the kind of attention that is needed are excessive. If problems are detected at some time and if more remedial medical action is required, I have no idea what the cost might be. I am not talking here about the care, the sense of uncertainty or any of the other psychological mal effects this experience has had on my family and on so many thousands of others, but just about the actual cost in real dollars. And yet, the government has felt no compulsion to help any of us. I think that is wrong. The government failed us, failed to warn us against DES, failed to protect us, and we had a right to expect that degree of protection.

In my judgement, the medical cost to parents and to children who are victims of DES should be borne through some governmental funding mechanism. Millions upon millions of dollars are being wasted every year for foolish programs and we all know it. Yet, the thousands of families who were victimized by the government's failure in the DES case are not helped. It is a disgrace and those medical bills that are directly related to DES should be paid for through a special governmental program, and no one can convince me otherwise.

I have supported the program for DES discovery and counselling in Bergen, N.J. the the Freeholders and the Women's Rights Information Center established. I moved at the freeholder level to support John Skevin and his colleagues in their fight to have the state meet some of its obligations, and, I am prepared to join in the fight to have the federal government relieve some of the fiscal burden that is being felt by so many people because they and their children were poisoned.

This generous government of ours, which has chosen from time to time to feed the people of the world, has turned its back upon so many of its own, and it is time we put that situation to rights. Payment of DES related medical bills ought to be a federal responsibility.

And, there is one other thing that I want to see as a result of my own experience, and I hope it will not take another misguided socialist like Upton Sinclair to point it out to us. We need laws and we need enforcement that will guarantee that there will never again be another DES situation for so long as this nation exists. When we turn on our tap, we have to have confidence that the water is clean. When a physician prescribes a medication, we must be able to have confidence that the capsule contains no poisons that will damage our offspring.

I do not regard this as a woman's issue. It is a human issue. It is a question of right.

DES and Science

Pregnancy Outcome in the DES-Exposed Offspring

Dr. Raymond H. Kaufman
Baylor College of Medicine, Houston, Texas

With the progression of time, it is apparent that the risk for the development of adenocarcinoma of the vagina and cervix in the woman exposed in utero to diethylstilbestrol is quite small. Concern has also been raised, however, regarding potential problems with childbearing in these women. On the basis of the finding of structural changes in the cervix in many of the DES-exposed women, a study using hysterosalpingography to investigate the size and shape of the uterine body was undertaken. Relationship between such changes and pregnancy outcome was studied. We found that slightly more than two-thirds of the women on whom x-rays were performed had changes in the appearance, shape, and size of the uterine cavity that differed significantly from the normal. These changes were related to these structural abnormalities seen in the cervix and to vaginal epithelial changes. In other words, the woman who had vaginal epithelial changes or structural changes in the cervix was more likely to have an abnormally shaped uterine body.

One hundred nineteen pregnancies had occurred in the two hundred sixty seven women on whom x-rays had been performed. Excluding the pregnancies terminated by elective abortion, we found that only 45% of these pregnancies resulted in term deliveries. When compared to a group of non-exposed control women, it was obvious that far fewer of the DES-exposed individuals delivered term infants than did the non-exposed women. We have noted that the occurrence of ectopic pregnancy, spontaneous abortion, and premature delivery was higher in the stilbestrol exposed offspring than in the non-exposed woman. A comparison was then made between pregnancy outcome in women with normal x-rays and those with abnormal x-rays. It was observed that women with abnormal x-ray findings had more ectopic pregnancies, spontaneous abortions, and premature deliveries than the group of women with normal x-rays. However, the numbers of patients studied and numbers of pregnancies in both these groups were too small for the differences to be statistically significant.

For the moment, no specific treatment can be recommended. It would seem as if the majority of stilbestrol exposed women who desire to have children can become pregnant without difficulty and will ultimately deliver a normal infant. However, there may be a certain small percentage of these women who have a history of mid-pregnancy miscarriage or premature delivery on whom a cervical cerclage (a stitch is placed around the cervix to close the canal) may be of benefit.

Editor's note: Dr. Kaufman's material will be published in the American Journal of Obstetrics and Gynecology.

In the next Voice, we will discuss the pregnancy outcome of 71 DES daughters who volunteered for the University of California San Diego study, conducted by Dr. Larry Cousins.

Future analysis of pregnancy outcome in large numbers of DES exposed women is necessary to clarify these recent findings.

Medical Abstracts

1. Gill WB, Schumacher GFB, Bibbo M, Straus FH and Schoenberg HW, "Association of Diethylstilbestrol Exposure in utero with Cryptorchidism, Testicular Hypoplasia and Semen Abnormalities," *J. Urology,* 122:36-39, July, 1979

This follow-up report compares 308 DES sons and 307 non-DES sons whose mothers all participated in the original prospective, randomized, double-blind study of the effects of DES on pregnancy which was conducted in Chicago by Dieckmann in the early 1950's. DES sons had a statistically significant increase in the number of epididymal cysts (the epididymis is behind the testis and stores mature sperm cells). A small number of these cysts were examined further and no malignancies were found. DES sons had significantly more testicular abnormalities; notable, hypoplastic (underdeveloped) testes and cryptorchidism (undescended) testes. DES sons had significantly fewer sperm and the overall quality of semen (sperm count, sperm motility, motility grade, and the sperm structure and form) was significantly more abnormal. Both of these latter findings were more striking in men who also had underdeveloped testes. The importance of this study is that it clearly demonstrates reproductive system abnormalities in sons whose mothers were given DES. These changes "may well impair fertility in a certain number of patients," although it "will probably be another decade before the actual infertility rate is known." No cancers were found in this group of DES sons; however, the authors point out that "the increased incidence of cryptorchidism and hypoplastic testes increases the risk of carcinoma of the testes."

2. Hinman F., Unilateral Abdominal Cryptorchidism, *J. Urology,* 122:71-75, July, 1979

The author reviewed available literature on treatment options for patients with unilateral abdominal (non-palpable) cryptorchidism (i.e., patients with one undescended testis in the abdominal cavity which cannot be felt by physical examination). He points out that the risk of testicular cancer is 35 times greater for persons with any type of undescended testis than for the general population, and that although only about 15% of undescended testes are intra-abdominal, this type accounts for half of the cancers. Fertility problems are also evident in patients with cryptorchidism and the author points out that if an operation to bring down the testis is done to preserve fertility, it should be done before the patient is 5 or 6 years old. However, in the special case of non-palpable undescended testis, he does not feel that such an operation will improve fertility because in these cases the testis is basically abnormal. In addition, the increased risk of cancer for these patients warrants complete removal of the testis followed by cosmetic surgery (a silicone prosthesis).

Fill out the enclosed coupon on p. 7 — We Need Your Support

DEAR DOCTOR . . .

We are grateful to Dr. Norma Perez Veridiano of Brookdale Hospital Medical Center, Brooklyn, N.Y. for responding to these questions.

1. My mother was advised by her doctor that she was given DES thirty years ago when pregnant with me. My own doctor sees no DES related abnormalities. I have never been examined by a colposcope. Is it necessary that I have regular DES examinations?

I think it is very important that every DES patient have a regular DES examination. A regular DES examination does not absolutely have to include colposcopy. What is important is that the doctor giving the examination is fully aware of the different known effects of DES on an exposed daughter. Colposcopy, if available, is helpful, but there are other tests such as iodine staining, digital palpation of the vagina and pap smear which are just as important.

2. I am a 27 year old DES daughter. I have been unable to conceive. Are there any precautions that I should be aware of in a fertility work-up? Can I take hormones?

I know of no precautions that you should be aware of in a fertility work up. Are you referring to the hysterogram and its possible radiation exposure risk? If you are, most authorities believe a regular hysterogram test done in the first part of the cycle has minimal radiation hazards. Insofar as hormones are concerned, I would not advise my patient to take any form of estrogen to improve cervical mucus. I feel that if you are exposed to any type of estrogen in the cycle in which you become pregnant, then the fetus will again be exposed to estrogen hormones.

Continue to send your medical questions to the Voice.

Did you "Ask Your Mother?"

Linda Kelsey, who plays a news reporter on the CBS program "The Lou Grant Show," was featured in the first dramatic program about DES. The national exposure was a most significant advance in public and professional education about DES. Although the show emphasized obtaining documentation of drug records, it proved highly successful in urging daughters to seek DES screening examinations. Members of DES ACTION/San Francisco were story consultants. (see a subscriber's reaction in "Letters to the Editor")

Be An Enlightened Medical Consumer

PERIOD • by Jo Ann Gardner-Loulan, Bonnie Lopez, and Marcia Quackenbush "Learning to love your own specialness is a big part of growing up."

A positive and accepting treatment of menstruation, anatomy, and pelvic exams is available in **PERIOD.** This book is refreshing in its healthy approach in dealing with the physical changes and the emotional gamut that may accompany growing up female. The underlying theme of knowing how your body works makes growing up and going through all the changes easier is especially appropriate for the young DES daughter. Of particular note, **PERIOD** focuses upon the first internal exam and offers the following advice: "Just like regular visits to the dentist, having a pelvic exam is very important. Many physicians think the best time to start having pelvic exams is after your first menstrual period. It is always better for your body to be checked regularly instead of waiting until you're sick. Regular check-ups can prevent sickness, and that's important! (Reprinted with permission from **PERIOD.** Available at bookstores and by mail from New Glide Publications, 330 Ellis St., San Francisco, Ca. 94102)

The Voice would appreciate your sharing other books and sources that helped prepare young DES daughters for their necessary examinations.

Letters to the Editor

DEAR VOICE:

Thanks for all your work. Did you have anything to do with the Lou Grant show? I thought it was very good and stuck pretty close to the facts, though I had never heard of the ovaries having to be removed — ?

Mrs. H.

Lou Grant Series
CBS
51 West 52nd
New York, New York 10019

Thank you for your excellent program last night about DES.

I am a DES mother with four DES children — two daughters and two sons. I learned about DES when the girls were in their teens and have watched them carefully since then. I learned the hard way that a simple physical examination and Pap smear was not sufficient, that it takes a specialist with a special instrument and examination (colposcopy).

For a long time I said, "Thank God the last two were boys," and then I began reading about DES sons. I hope you do a sequel about the DES exposed males. Can you imagine what it is to find out that your son and his lovely young wife can never have children, that he is sterile? It is just as traumatic for a boy as it is for a girl.

They will not say definitely that sterility is caused by DES exposure. They couch their words very carefully. They say, "There is an increase in sterility among DES exposed males." There is also an increased risk of cancer in the male genitals. They need to be checked frequently for epididymal cysts and cancer lesions.

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☐ I wish to support DES Action activities further. Enclosed is my additional contribution of _____ .

Name _____

Address _____

I hope in your follow-up programs on DES that you cover "the pill" and DES exposed women. Any young girl can go to a Planned Parenthood Center or off-beat physician and get "the pill." No history is taken. No questions asked. But if a girl has been exposed to DES *in utero*, taking the pill is like pouring gasoline on a fire.

You can understand why I have been following this very closely and doing quite a bit of research on DES exposure. I firmly believe when all the facts are in the long-term effects of DES will be more devastating than the thalidamide babies. They are calling these conditions "delayed birth defects."

We don't know yet about our youngest son. They say, statistically he has a good chance of being alright. But what does it matter if the statistics are low, if you are that statistic?

Thank you for publicizing this situation. There are so many who have no idea what they took, how much, or when. I was fortunate. I knew I had taken it. My doctor died and his records had been destroyed, but I was finally able to document that I had taken it from my hospital records. I couldn't get to them until after the Freedom of Information Act was passed.

Last fall I gave an interview to the medical reporter for our local newspaper. I gathered all the information I had on DES, but refused to let him use our name. Not one word was printed. I know what a big obstetrics practice my doctor had, and I know he used DES liberally. I also know there were other doctors here who prescribed it, too. But how do you reach them if your local newspaper will not cooperate? I only hope some of them were watching your program last night. Thank you again, and please do some follow-up programs.

If you should want to publicize this letter, please do not use my name — for the sake of my daughters who have DES symptoms, and my handsome, healthy son who is sterile.

Loose Ends

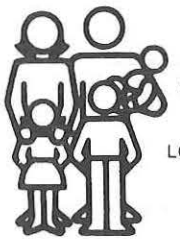
Women USA's Hotline is now in operation. Dial this nationwide toll free number 800-221-4945 to hear a timely information and action message on an important women's issue. By enabling women across the country to react quickly to a call for action, they hope to make the majority voice of women heard more effectively in Washington and nationally. Get the Hot Line Habit. Hopefully we can utilize this service when we need to reach women nationally concerning DES. Women USA will also be lobbying in Washington on issues that affect women's economic, political and social status.

Oklahoma will be introducing a DES bill. California has also recently introduced legislation.

A new chapter is being activated in Westchester County: Contact Eva Foster c/o Dr. Lane - 682-2402. They are compiling a list of Westchester physicians and are liaison with screening center.

Dr. Arthur Herbst, head of the Registry for Hormonal Transplacental Carcinogenesis, which was established to investigate DES-related cancers, has joined the Medical Advisory Board of DES ACTION/National. Dr. Herbst was one of the first physicians to publish articles concerning the link between DES exposure and vaginal cancer, and he continues to be a major figure in DES-related research.

DES ACTION acting president, Nancy Adess, was featured in the January, 1980 issue of *Ms. Magazine* as one of eighty "Women to Watch in the 80's." The *Ms.* feature highlighted Nancy's work with DES ACTION/National and the DES ACTION office at the Coalition for the Medical Rights of Women in San Francisco. Nancy believes that the award indicates the growing public awareness of the DES situation and recognition of the impact of our organization.



DES ACTION

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