DES ACTION VOICE

Winter 1987 A Focus on DIETHYLSTILBESTROL Exposure Issue #31

Another Safe Hormone?

By Kari Christianson, President DES Action USA

From time to time DES Action hears of health and pharmaceutical issues in addition to DES which warrant our interest and attention. The subject of Bovine Growth Hormone is one such complex issue.

Bovine Growth Hormone (BGH) — also known as Bovine Somatotropin (BST) — is a hormone which, the pharmaceutical industry claims, will increase dairy cows' milk production by 10% to 40%. The hormone must be administered by a daily injection.

In the United States today there is a surplus of milk and dairy products — too much milk at too low a price, driving many dairy farmers out of business. Furthermore, the proposed use of Bovine Growth Hormone raises concerns both for the health of the cows being "treated" and that of the consumers being exposed to the milk products resulting from BGH use.

In order to take a close look at these farm and consumer issues, the Wisconsin Family Farm Defense Fund sponsored a national conference in Madison Wisconsin on October 11, 1986, entitled, "Economic and Ethical Impact of Biotechnology on Agriculture in Wisconsin." As DES Action USA's President, I attended and spoke at a workshop on the questions the DES story raises for this new technological intervention.

The conference brought together outspoken critics of biotechnology, including a keynote address by Jeremy Rifkin; scientists and students of biotechnology from the University of Wisconsin; and farmers and consumers. This "mixed bag" of participants at the conference made for lively discussion groups and for some unusual alliances.

Farmers who may have used DES as a growth stimulant in animals were siding with a consumer who questioned all hormone use in humans and animals. Animal rights activists, who oppose all animal experimentation, were offering moral support to a DES daughter who believes that there is much to be learned about DES exposure by forcing such exposure on laboratory mice. Scientists, some of whom were offended and personally affronted that anyone would question their ethics or decision-making standards, were confronted by people who feel it is both right and necessary that those who are to use — to be exposed — to a pharmaceutical product be involved in the questioning and evaluation of its use.

There were four workshops at the conference: The Economic Impact of Biotechnology; The Regulation of Biotechnology; The Relationship between the University Research Effort and the Chemical Industry; and Human Health, Animal Health, and Environmental Issues Surrounding Biotechnology. The following is a portion of my presentation at the workshop on the human health topic:

"I am here today representing the voice of the consumer and a voice with specific experience with a previous growth hormone — DES, diethylstilbestrol — a synthetic estrogen. As a recipient of what was the hormone technology of a generation ago, I know firsthand the dangers of assuming that a hormone is safe — until years down the road when the truth and the deadly health consequences become known. DES is a pharmaceutical tragedy of unequalled pro-

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Inside

Get Into the Action

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

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

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Keeping Your Own Records

Consumers have trouble getting their own medical records. Doctors and hospitals frequently are reluctant to share that information with the consumer, the person most deserving to know, claiming that she/he won't understand the technical language, or will be scared away from so-called needed procedures by the record's contents. That's why the People's Medical Society has just published *Your Medical Record*, a bulletin showing the consumer how to keep her/his medical history in her/his own words.

Your Medical Record has eight pages of charts and instructions, with special sections including space to record every physician visit, diagnosis and treatment; lab tests and x-rays, dental and eye exams, family medical history, and emergency phone numbers. There is also room to list all prescription and non-prescription drugs, and a "Condition Profile Checklist" for creating an individual medical profile. *Your Medical Record* is available for $3 from People's Medical Society, 14 East Minor St., Emmaus, Pa. 18049. ■

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Medical Abstracts: More Hints About Possible Effects of DES

By Judy Turiel, Ed.D.

R. Kaufman, E. Adam, K. Noller et al, Upper genital tract changes and infertility in diethylstilbestrol-exposed women. American Journal of Obstetrics & Gynecology, *vol. 154 (June, 1986) 1312-8*

Studies using uterine x-rays (Hysterosalpingograms or HSGs) have demonstrated abnormalities in size and shape of the uterus in approximately 40% of DES daughters. Women with these abnormalities are more likely to have difficulty carrying a pregnancy to term than DES daughters with "normal" HSG results. The present study asked whether DES-daughters with an abnormal HSG have greater difficulty conceiving than do women with normal findings.

The study found that an abnormal x-ray, in general, was not associated with infertility (defined as one year or more of unsuccessfully attempting pregnancy). A similar number of women with normal and abnormal x-rays had difficulty conceiving, and women who did conceive were as likely to have an abnormal as a normal x-ray. In other words, you could not predict infertility on the basis of a normal vs. abnormal x-ray.

However, when the abnormal hysterosalpingogram group was broken down into specific uterine alterations, those with "constriction" of the upper uterine cavity did have a greater likelihood of infertility — 2.26 times the likelihood, compared to those without constriction. Constriction *and* a T-shaped uterus increased the chance of infertility a little more, although the T-shape alone was not associated with difficulty conceiving. Within the "abnormal" x-ray group, then, the two specific types of uterine anomaly accounted for the greatest amount of infertility.

Studies of infertility are notoriously difficult to design and evaluate, due to problems of definition, follow-up of patients, and bias in selection of the sample chosen. While the authors note such problems, their report does suggest that certain uterine anomalies may lower the fertility of DES-daughters. However, there is no recommended treatment for the conditions described in this study, nor is routine hysterosalpingogram recommended for DES-daughters. If such a procedure is done as part of a total infertility workup, information on an individual's specific uterine abnormality may help determine her chances for successfully conceiving a pregnancy.

This study demonstrates the importance of considering sub-groups within the overall DES-exposed population who — for reasons as yet unknown — may experience health effects in greater number and/or intensity. Only then can we gain a thorough understanding of the range of health consequences related to DES-exposure.

A.F. Haney, R. Newbold, B. Fetter, and J. McLachlan, Paraovarian cysts with prenatal diethylstilbestrol exposure — Comparison of the human with a mouse model. American Journal of Pathology, *vol. 124 (Sept. 1986) 405-11*

Research on longterm effects of prenatal DES-exposure takes a variety of forms. Some studies look directly at DES-daughters and sons. Often, the number of individuals studied is small, and can provide only hints, suggesting possible pieces of the DES puzzle which need further study in larger, well-controlled samples. Hints about DES-effects come also from studies using laboratory animals in experiments designed to parallel human exposure. An ongoing question in animal studies is whether an observed DES-effect will or will not also be seen in exposed humans.

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First DES Lawsuit Abroad

In a landmark action, six DES daughters in the Netherlands who have had cancer have filed suit against ten drug companies. This is only the second product liability suit ever filed in that country for a pharmaceutical product. The basis for liability is the theory of group liability, but under Netherlands law, other issues such as negligence, foreseeability and causation will be raised.

The Dutch system differs markedly from the U.S. legal system. There is no jury; the statute of limitations is 30 years, starting at age 21; punitive damages are unknown and damages for pain and suffering usually do not exceed 100,000 guilders — $45,000 — (medical costs are covered by national health insurance); and there are no contingency fees: state-financed legal aid is available.

DES Aktiegroep of the Netherlands sees this suit as a way to raise public awareness about DES and about the issue of drug safety and effectiveness. For the daughters who sue, according to DES Aktiegroep, "it is very important to be able to do something, to act instead of just 'being the victim,'" One of the women stated this very clearly by saying, "It gives me such a good feeling to read all the headlines in the newspaper about us suing the industry. We turned from victims into the attackers."

The awareness goal was realized immediately — Hundreds of women contacted DES Aktiegroep for information. "Most of them just now found out that they were exposed as well. Among them there were five DES daughters who have had cancer and are interested in joining the lawsuit." ■

Hormones continued . . .

portions in this country. But I recognize that there are lessons to be learned from the tragic legacy of DES use that can be applied to BGH development.

I am not convinced by the argument that BGH is safe and does not affect cows or humans because it is a hormone that occurs naturally in dairy cows. Estrogen is a hormone which occurs naturally in women, but we now know the consequences of administering additional synthetic hormone to pregnant women. Substitute the word 'biotechnology' for 'synthetic' — what you have is giving *more* hormone to the animal than is naturally produced by that body.

In the case of DES as an animal growth stimulant, the hormone was allowed on the market and on the table without sensitive residue testing being available. If we cannot find hormone residue, does that mean that it does not exist? Is there a 'safe' exposure limit to a known carcinogen, a cancer-causing agent, such as DES is? Is this DES situation one that we want or can afford to have repeated with other hormone residues?

I am not suggesting that BGH is a potential carcinogen, but I am suggesting — demanding — that we evaluate the health impact and potential consequences before we allow this product of biotechnology to reach our food supply. Do tests exist that can trace residues of BGH in milk? And who sets the standard for safe limits of residues? Will we let the pharmaceutical industry, those with a financial stake, dictate levels of safety? Federal and state regulations are ignored or non-existent in dealing with the issues of testing and sale. In the case of BGH we must look at who will be particularly vulnerable to any residues in milk and dairy products. At the very least, we must demand that the health impact be determined for pregnant women, for the developing fetus, and for children.

The irony of this situation, of course, is that we, the consumers, do not want BGH in our food supply, nor do we want the increased dairy product which results from BGH use. But if we are to be dragged kicking and screaming into the age of biotechnology in food and the use of BGH, then let us demand *all* the answers. It is appropriate that we ask these questions about human health and safety. And it should be mandatory that answers are provided before any 'new' hormone residues are introduced into the human food supply."

In the discussion which followed, my questions were dismissed (nicely) by the scientists as being naive and unanswerable. My response was that their inability or lack of desire to address these questions in research was itself an answer — albeit an unsatisfactory one. In a final conversation, a University of Wisconsin scientist, whose sister and two nieces are DES exposed, tried to convince me of the safety of BGH because it is naturally occurring in the cow and, therefore, is in milk already. My response: "And estrogen occurs naturally in women but. . . . " ■

For more information about Bovine Growth Hormone write:
Wisconsin Family Farm
Defense Fund
Rt. 1, Box 49
Cazenovia, WI 53924

Abstracts continued . . .

While much of the animal research aims at defining *how* DES does what it does (the "mechanisms"), this research can provide direction for the development of human studies, which may, in turn, eventually contribute to health care applications.

A recent report in a pathologists' journal presents a fascinating combination of these two approaches. Paraovarian cysts (fluid-filled or solid sac located between the ovary and fallopian tube) in six DES-daughters were compared to similar cysts in experimental mice. The study represents an unusual collaboration between a clinician (Dr. Haney) and basic scientists at the National Institute of Environmental Health Sciences, all of whom have longstanding research interests in DES-exposure.

In four of the six DES-daughters who were found to have paraovarian cysts, the tissue examined was different in structure, or "histology," from cysts seen commonly in the same location among non-exposed women; the cysts were similar to those seen in DES-exposed mice. These cysts are of scientific interest because they are thought to arise from a different embryologic tissue than that usually associated with DES effects in humans. The findings demonstrate the need to monitor potential health consequences beyond those already identified in DES sons and daughters, since effects of prenatal exposure may be broader than is currently known.

The authors are careful to point out that "no clinical problems attributable to paraovarian cysts in the DES-exposed population have been noted." (p. 409) Rather, they are describing unusual tissue changes in the DES-exposed women which correspond to changes seen in the mouse model. The correspondence bolsters the value of each line of research to the other in learning more about DES-exposure.

In this small sample of women undergoing surgery for infertility, there was an increased frequency of paraovarian cysts in exposed women compared to the non-exposed, a finding also consistent with the mouse model. The authors speculate that the presence of paraovarian cysts could possibly contribute to infertility if, for example, the location of the cyst (near the feathery end of the fallopian tube) interferes with retrieval of the egg after ovulation. However, they point out that no one knows the frequency of paraovarian cysts in fertile women.

None of the cysts showed any suggestion of malignancy; still, the authors do recommend close surveillance of DES-daughters found to have such cysts, as for any unusual tissue change associated with DES-exposure.

Letters to The Editor

Reproductive Technology: A Physician Responds

Dear Editor:
Regarding the article by Anita Direcks, on Reproductive Technology (Voice #28, Spring, 1986) here are my comments.

I think I need to begin with a fundamental question: what are our present alternatives? We have no data on the long-term consequences. It is impossible to acquire these data at present, because there are no long-term results: the oldest child is 8 years old. However, acknowledging this ignorance is not meant to be a cavalier acceptance of the safety of these interventions. Rather, we are very interested in working with you and others to pursue these questions in meaningful ways. As you must be aware, the children born from IVF technology tend to be followed more closely throughout both pregnancy and follow-up; data is being obtained by the use of registers of IVF babies. The medical profession is committed to obtaining the kinds of data that will allow us to make conclusions about long-term safety. The short-term data are certainly reassuring, but I have not tried to project from these studies that long-term consequences might not appear. I know of no way to obtain these data without persevering and offering IVF as a therapy for the present.

I would strongly argue against the statement that IVF developments are similar to the story of DES. There are no data that support the efficacy of DES for maintaining pregnancies. On the other hand, in vitro fertilization is demonstrably successful for many women who have no other options. The other statement by Anita Direcks, that hardly any questions are being raised about the danger of this technology for the woman, is belied by this correspondence and by the fact that we're not alone in asking these questions.

The statement that no serious attention is being paid to the possible long-term effects of IVF on mother and child is not warranted. It is true that there are no data, but that doesn't mean that they aren't being diligently sought. It is impossible, as I said, to have any long-term effects known, when there are no long-term children. If we stopped IVF in order to acquire this data, we wouldn't have enough children to examine. If we could advise all of our patients to wait ten to twenty years for this information, then certainly we would do so. But this is obviously not a realistic choice for many of these infertile couples.

There may indeed be an action group for test-tube children within fifteen to twenty years. I sincerely hope not, but unlike DES exposed children, IVF children will in most cases owe their existence to this technology. I sincerely believe that.

I am trying to state my point as strongly as possible for two reasons. One, I think that there is a great deal more sympathy and concern than is apparently being perceived by some of your organization. The second reason why I want to state an opposing view is that I think it very important that individuals who have such an important perspective not antagonize the individuals that they want to educate and cooperate with. If statements that aren't founded in fact are made in a manner that might be perceived to be antagonistic, then any hope of mobilizing all of the physicians involved in IVF to develop a high level of concern and vigilance will be lost because they will consider the statements as lacking in credibility. I think this will be a misfortune.

Mary C. Martin, M.D.
Assistant Professor
Dept. of Ob/Gyn and
Reproductive Sciences
University of California
at San Francisco

Endometriosis Support Groups Encouraged

Dear Editor,

I am a DES daughter with endometriosis. I am recuperating from a hysterectomy at age 30 after a long history of surgery and hormone treatments. I was fortunate enough to have a child and also to keep a quarter of one ovary, however, at this point I am still frustrated by the entire experience.

Having endometriosis alone is bad enough. Coupling it with being a DES daughter just increases the worries, unbearably at times. I chanced keepng part of an ovary and having a recurrence of endometriosis because I didn't want to go on estrogen replacement therapy since I am DES-exposed.

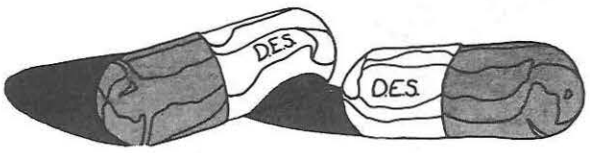
I know there are more of you going through my experience. I'm going to work locally to form a support group in Connecticut for DES daughters with endometriosis as well as for those with endometriosis alone.

I urge you to encourage your local DES chapter to help you do the same. If you are in Connecticut, write:

Laura Minor
88 Anderson Ave.
Forestville, CT 06010
or call 203-523-5275 (days)

Another resource is the Endometriosis Assn., P.O. Box 92187, Milwaukee, WI 53202

Sincerely,
Laura S. Minor



Some Lessons to Learn About Cervical Cerclage

by Connie Peabody

I am a DES daughter with a history of medical disorders, ranging from ectopic pregnancy to three miscarriages attributed to cervical incompetency. All but one took place in the 2nd trimester. Due to my incompetent cervix I must have a "cervical cerclage" performed to bring a pregnancy to term. I have carried one baby full term, live birth with this procedure. She is now five years old. My most recent miscarriage at 20 weeks was brought on by an infection introduced by the cerclage — a procedure that was performed to prevent miscarriage. I have since learned that such an infection can be prevented by the use of antibiotic vaginal creams and/or the prescription of low dose antibiotics throughout pregnancy.

DES Daughters need to be aware of the risks involved with the "cervical cerclage" procedure.

Risk #1: *infection* — can be introduced via the sutures used in the cerclage. Some physicians recommend the use of an antibiotic vaginal cream. Others recommend the use of low dosage antibiotics taken orally throughout the pregnancy. The effect of long term antibiotics on the fetus, as one might expect, is unknown at this time. (Sound familiar?) The antibiotic vaginal cream appears to me to be the least harmful of these two preventatives against possible infection in the cervical area.

Risk #2: With the cervical cerclage (as evidenced from my experience) is the potential to go into active labor with the stitches still intact. If these are not clipped in time, irreparable cervical tearing could occur.

Hopefully, voicing my tragic circumstances will spare some others the loss I experienced, due to improper medical supervision.

Be *cautious*, be *assertive*, be *selective* in choosing your personal physician and health plan!

I hope my experience will be of some help to someone else. ■

"Cervical Cerclage"

This procedure is made available to female patients with a diagnosed *incompetent* cervix, that is pregnancy cannot be carried full term, without the cervix thinning & eventually dilating prior to an optimum gestation period. The cervix is literally stitched up, much like the strings on a purse, around the cervix. Hence the name "purse string" procedure, but also "cervical sling," "McDonald Procedure" and more commonly known as "cervical cerclage." This procedure is usually done at about 14-16 weeks.

— C.P.

How Cost-Benefit Analysis Works

In 1977, a group of workers learned they had become sterile while manufacturing the chemical DBCP for Occidental Petroleum Co. in central California. A lawsuit filed by those workers has recently unearthed a 1978 internal company memo which describes how they calculate costs and benefits. The document, written by the Director of Health, Safety and the Environment suggested that Occidental take the following steps:

- calculate how many people would be exposed to DBCP
- assume that a normal proportion of them would become sterile or get cancer and that half of those would sue
- then figure how much the company would have to pay in judgments, settlements and legal fees.

The memorandum then concludes, "Should this product still show an adequate profit meeting corporate investment criteria, the project should be considered further.

from the *San Jose Mercury*
November 20, 1985
San Jose, California
(Thanks to *Silicon Valley Toxics News*)

A Sad Note

DES Action notes with sadness the passing of Aimee Edelman, leader of DES Action, Cleveland. Aimee was a lively and committed volunteer, who accomplished a great deal on behalf of DES exposed people in Ohio. Our sympathy goes to Aimee's family and friends.

DES Screening Center Breast Screening Program

By Paula DiStabile, R.N.

Shortly after the 1984 *New England Journal* report of an increased breast cancer risk in DES exposed mothers, the staff of LIJ's DES Screening Center began work on a program that would address their needs.

A needs assessment survey was sent to every client on our mailing list. The impressive response by DES exposed mothers confirmed our suspicions that many women were unsure about the thoroughness of their breast exams, had not had medically advised mammography and did not practice Breast Self Examination regularly. The mothers told us that they wanted a center where expert breast examination and mammography would be available, and where individualized counseling about and teaching of BSE by nurse practitioners would support their practice of this lifesaving technique.

The New York State Department of Health graciously agreed to fund a pilot program. Our first clinic session was held in October 1986; nearly twenty women were screened in that one night.

Mothers are referred for mammography, if indicated, prior to their appointment. They come in with the report and/or mammogram films. After taking a brief health history the nurse practitioner introduces the patient to one of the two breast specialists on staff. A thorough breast exam is done with the nurse practitioner present, so that she can use the physician's findings in tailoring her breast self examination teaching to the woman's particular breast tissue patterns. Mammography results are reviewed, and the physician, nurse practitioner and client formulate a follow-up plan.

Breast self exam is then taught to the woman and/or a partner of her choice. Teaching is tailored to the individual's need. For our high risk clientele, the center emphasizes the additional benefits of examination by an expert in breast care. "I've *never* had an exam like that before!" is the usual comment by our clients. Mammography, when indicated, close follow-up, and nursing support are also essential components of the service. ■

The DES Screening Center's Breast Screening Clinic at Long Island Jewish Medical Center is currently being held once a month, but more sessions may be added when necessary. All local DES exposed mothers are welcome. Fees are charged on a sliding scale basis determined by income. Those with insurance are assisted in obtaining reimbursement. Medicaid and Medicare are accepted. No client will be turned away for inability to pay. For appointments or more information, contact the DES Screening Center of Queens, Nassau and Suffolk Counties, 410 Lakeville Road, Room 105, New Hyde Park, New York, 11042, (718) 470-8880. ■

Editor's Note: *This is a wonderful example of an important service hospitals, in conjunction with their state health departments, can provide DES mothers. Check with your hospital to urge them to undertake such a program.*

JOIN DES ACTION

Enclosed is my tax-deductible membership. All members receive a copy of the *DES Action Voice* four times a year. Make checks payable to **DES Action** and mail to:
Long Island Jewish Medical Center, New Hyde Park, NY 11040.

☐ Subscriber: $20-$40 sliding scale	Receives subscription to the *DES Action Voice* quarterly newsletter.
☐ Friend: $50-$250	Receives the *Voice* plus *DES: The Complete Story* by Cynthia Orenberg.
☐ Supporter: over $250	Receives all of the above plus annual reports on the organization's progress.
☐ Pledge: _____ per month/quarter (circle one)	Receives the *Voice* plus DES Action gift.

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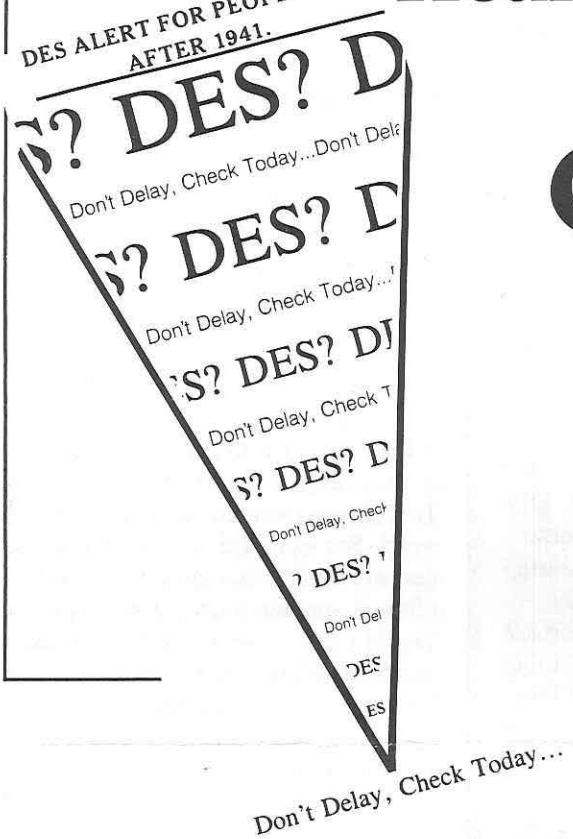
I am a ☐ DES Daughter ☐ DES Son DES Mother ☐ Other

Ohio's DES Public Service Health Program



Ohio's Dept. of Health has a DES Program featuring posters and booklets, TV and radio spots, press releases to hospital, clinic and pharmacy newsletters, health fairs, workshops for doctors and nurses, and messages on the payroll summary cards sent to every state employee. Funding also includes materials the four DES Action chapters distribute in their outreach.

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