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# DES ACTION VOICE

Issue #22

A Focus on DIETHYLSTILBESTROL Exposure

Fall 1984

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Editorial

## Whose Hardship?

by Pat Cody

Earlier this year, the New York State Court of Appeals handed down a decision that two DES daughters who had suffered DES-related cancer could not recover damages because they missed out on the 3-year statute of limitations. This law imposes a time limit of 3 years on filing personal injury suits from the time of exposure to a substance, or from the age of majority, whichever comes later. The Court's opinion in the DES case was that changing the statute to make it possible to sue if an injury had occurred after the statute had run out was a matter for the legislature rather than the courts. Chief Justice Lawrence Cooke dissented, saying that the existing law is being used "as a shield behind which a court may hide as reason for perpetuating unnecessary and profound unfairness."

Now, a recent headline tells the story: "Politics ready to kill legislation for chemical exposure victims" (*Times-Union*, Albany, NY). Once again, the Republican-dominated state Senate turned down a bill that would do just what the court indicated — change New York state's out-dated product liability rules. Under this bill, the existing 3-year legal time limit for filing lawsuits would be changed so that the time would start when the victim discovers the effects of exposure. Under the present law, in cases of DES exposure, a person filing a suit for injury from the drug had three years from the age of majority (18). If their injury occurred after age 21, they were out of luck.

Noting concern that the bill "would pose financial hardships for businesss that might be sued," Republican Senate leader Warren Anderson once

again engineered the defeat of the measure. Since the businesses that might be sued are for the most part giant corporations involved in manufacturing drugs, asbestos, and pesticides, among other potentially hazardous products, they are not small companies at risk for "hardship." Rather, it is the victims of these companies, including DES daughters with thousands of dollars in medical bills, who suffer the hardship.

The New York Public Interest Research Group, a Nader affiliate, led the effort to support the legislation. After it was defeated, their coordinator, Karen McMahon, wrote:

[the Senators'] concern lay in protecting the industries that had negligently exposed innocent people to toxic and often lethal substances, rather than protecting the health and well-being of New York State residents.

Then, McMahon adds,

We will not give up. We plan to make this a campaign issue in November; we're holding our representatives accountable for their actions. The campaign continues on, and we encourage and welcome your energy and determination.

This is an important issue for all DES exposed, wherever you live, because of the precedent it can set for other states that have restrictive laws (and many do). Product liability laws need to be matched with present-day hazards: high responsibility must accompany high hazards.

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## Get Into the Action

DES Action National 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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# A Plea for Corporate Conscience

*The Dalkon Shield intrauterine device (IUD) was marketed widely in the United States following falsified tests assuring its safety. In the early 1970s, the first reports appeared of women who became pregnant with the Dalkon Shield in place suffering septic (infected) miscarriages. Some of these women died; many others had to undergo emergency hysterectomies. In the years that followed, many women brought suit against the A. H. Robins Company, manufacturer of the Dalkon Shield, for their injuries.*

*On February 29, 1984, Chief U.S. District Court Judge Miles W. Lord of Minneapolis, Minnesota addressed the three top officers of the A. H. Robins Co. in approving a \$4.6 million settlement of seven product liability*

*cases involving the Dalkon Shield IUD.*

*We reprint here excerpts from the Judge's remarks because they seem to us applicable not only to the manufacturers of the Dalkon Shield, but also to those who manufactured DES, and to those who have manufactured and distributed other medical drugs and devices that, because of improper testing and enthusiastic marketing, have caused untold harm.*

*DES exposed women who have sought compensation for injuries they thought related to their DES exposure may see similarities between the defense tactics described here and those they may have experienced in their own cases.*

"Mr. Robins, Jr., Mr. Forrest and Dr. Lunsford: After months of reflection, study and cogitation — and no small amount of prayer — I have concluded it perfectly appropriate to make to you this statement, which will constitute a plea to you to seek new horizons in corporate consciousness and a new sense of personal responsibility for the activities of those who work under you in the name of the A. H. Robins Company.

It is not enough to say, "I did not know," "It was not me," "Look elsewhere." Time and time again, each of you has used this kind of argument in refusing to acknowledge your responsibility and in pretending to the world that the chief officers and the directors of your gigantic multinational corporation have no responsibility for the company's acts and omissions . . .

Gentlemen, the results of these activities and attitudes on your part have been catastrophic. Today as you sit here attempting once more to extricate yourselves from the legal consequences of your acts, none of you has faced up to the fact that more than 9,000 women have made claims that they gave up part of their womanhood so that your company might prosper. It is alleged that others gave up their lives so you might prosper. And there stand behind them legions more who have been injured but

who have not sought relief in the courts of this land.

I dread to think what would have been the consequences if your victims had been men rather than women, women who seem through some strange quirk of our society's mores to be expected to suffer pain, shame and humiliation.

If one poor young man were by some act of his — without authority or consent — to inflict such damage upon one woman, he would be jailed for a good portion of the rest of his life. And yet your company, without warning to women, invaded their bodies by the millions and caused them injuries by the thousands. And when the time came for these women to make their claims against your company, you attacked their characters. You inquired into their sexual practices and into the identity of their sexual partners. You exposed these women — and ruined families and reputations and careers — in order to intimidate those who would raise their voices against you. You introduced issues that had no relationship whatsoever to the fact that you planted in the bodies of these women instruments of death, of mutilation, of disease . . .

Mr. Robins Jr., Mr. Forrest, Dr. Lunsford: You have not been rehabilitated. Under your direction your company has

in fact continued to allow women, tens of thousands of them, to wear this device — a deadly depth charge in their wombs, ready to explode at any time. Your attorney Mr. Alexander Slaughter denies that tens of thousands of these devices are still in the bodies of women. But I submit to you that Mr. Slaughter has no more basis for his denial than the plaintiffs have for stating it as truth, because we simply do not know how many women are still wearing these devices and your company is not willing to find out. The only conceivable reasons you have not recalled this product are that it would hurt your balance sheet and alert women who already have been harmed that you may be liable for their injuries. You have taken the bottom line as your guiding beacon and the low road as your route. This is corporate irresponsibility at its meanest . . .

I see little in the history of this case that would deter others from partaking of like acts. The policy of delay and obfuscation practiced by your lawyers in courts throughout this country has made it possible for you and your insurance company, Aetna Casualty and Surety Company, to delay the payment of these claims for such a long period that the interest you earn in the interim covers the cost of these cases. You, in essence, pay nothing out of your pocket to settle these cases. What other corporate officials could possibly learn a lesson from this? The only lesson could be that it pays to delay compensating victims and to intimidate, harass and shame the injured parties . . .

Please in the name of humanity lift your eyes from the bottom line. You, the men in charge, must surely have hearts and souls and consciences. If the thought of facing up to your transgression is so unbearable to you, you might . . . confess to your maker, beg forgiveness and mend your ways.

Please gentlemen, give consideration to tracing down the victims and sparing them the agony that will surely be theirs."



# Finding the Answers

Over the years, DES Action has received thousands of inquiries from DES mothers, daughters and sons asking if a particular health problem might be related to DES exposure. In too many cases, our answer must be, "No one knows." We do know that many conditions are probably not related to DES exposure. With so many people exposed, we expect to see the usual range of physical and psychological problems that appear among the general population. At the same time, these "anecdotal" reports do concern us, particularly when they begin to sound repetitive.

We are not comfortable with the view, expressed by some, that "DES exposure is no longer a problem." We heard that assurance a few years ago, when the risk of vaginal cancer in young DES daughters fortunately proved lower than some of the initial estimates. Only later did medical journals confirm what DES Action was hearing anecdotally — a higher than expected incidence of reproductive problems among DES

daughters and, perhaps, sons.

DES Action is now taking steps to help identify whether certain health conditions — beyond those already known — appear more frequently among DES exposed women and men than among non-exposed people. We want to document and count the stories that mothers, daughters and sons have been telling us. The Health History questionnaire on page 5 and 6 is an important first step. The survey is informal. It is *not* intended to be a scientific study. Your responses will provide a crucial "first look." If any trends are suggested by the answers we receive, we will discuss this information with scientists who can follow up with further studies.

We have listed a large number of possible conditions, to help you remember your own health history. We encourage you to add others you have experienced. Remember, most have *not* been associated with DES exposure, and we are *not* suggesting that they are related. We hope that DES-related conditions

are, indeed, "no longer a problem," other than those already known. However, many investigators studying DES emphasize the need to carefully monitor the health experiences of DES exposed men and women. We agree. This prudent action may help catch problems early, determine whether conservative preventive measures are possible, and avoid treatments that, with better understanding of DES exposure, prove to be unnecessary or harmful. In this way, we can all gain reassurance.

Older members of the generation exposed *in utero* to DES have too often found themselves saying, "If only they had known about this condition a little sooner." It is now clear that "we" must participate with "them," so that our health problems are neither overlooked nor overtreated throughout our lifetime. DES exposed individuals can help maintain a focus on this population's health needs. Please fill out the questionnaire as completely as possible if you are a DES mother, daughter, or son.

## DES Registry Established in Ontario, Canada

University of Toronto researcher, Dr. A. Dennis DePetrillo, has received funding from the Ministry of Health in Ontario, Canada, to design and establish an information registry on the incidence and effects of exposure to DES in that province.

Dr. DePetrillo, a gynecological cancer specialist, has been awarded the grant to collect data from clinics where DES daughters have received gynecological examinations. His data will be used to ascertain the rate of DES use in Ontario and to gather follow-up information on reproductive function and development of tumors in DES daughters.



The registry will be part of the DES Information Center being set up at Toronto's Wellesley Hospital in consulta-

tion with the University of Toronto and the Society of Gynecologic Oncologists of Canada.

The Ministry of Health's press release about this new project concludes, "The establishment of this registry offers considerable potential for new research on DES, such as the long-term health effects of DES exposure on parts of the body other than the reproductive system, and the hormone's impact on the health of DES daughters' own offspring."

This registry is an important first in Canada, and we eagerly look forward to the reports it will present as its data collection progresses.

# Health History Questionnaire

DES ACTION wishes to compile information on the health experiences of women and men who know or think they are DES-exposed. Many conditions will not be related to DES exposure. However, collecting clues in this way can help us alert the scientific community to possible areas of needed research. We hope you will help us with this project by filling out the following questionnaire *about yourself only*. If you need extra room, please use the comment section or additional sheets. Also, please pass a copy of this questionnaire to any DES-exposed person you know. (For example, your mother, child, brother, or sister.) Thank you.

Are you a DES-exposed:

Mother  
Daughter  
Son

Know for sure

( )  
( )  
( )

Think I am

( )  
( )  
( )

Have you ever tried to obtain medical records to verify DES exposure? \_\_\_\_\_ Did you receive the records? \_\_\_\_\_

Date of birth: \_\_\_\_\_

How many episodes of cold or flu have you had in the last year? \_\_\_\_\_

Have you received antibiotics in the last year? \_\_\_\_\_

If yes, for what reason? \_\_\_\_\_

Have you ever had a biopsy? \_\_\_\_\_ Of what? \_\_\_\_\_ At what age? \_\_\_\_\_

Please check if you have had any of the following conditions. *If possible, please also state at what age they were first discovered.*

## EVERYONE

- \_\_\_\_ Allergies
  - \_\_\_\_ mild
  - \_\_\_\_ moderate
  - \_\_\_\_ severe
- \_\_\_\_ Asthma
- \_\_\_\_ Arthritis
- \_\_\_\_ Diabetes, self
- \_\_\_\_ Diabetes, your mother
- \_\_\_\_ Diabetes, other family member
- \_\_\_\_ Kidney or bladder problems
- \_\_\_\_ Lupus
- \_\_\_\_ Multiple sclerosis
- \_\_\_\_ Herpes (including shingles)

## MOTHERS ONLY

- \_\_\_\_ Thyroid problems
- \_\_\_\_ Cystic (lumpy) breasts
- \_\_\_\_ Breast cancer
- \_\_\_\_ Cancer of the uterus
- \_\_\_\_ Other cancer: \_\_\_\_\_
- \_\_\_\_ OTHER conditions: \_\_\_\_\_

## SONS ONLY

- \_\_\_\_ Undescended testicle
- \_\_\_\_ Epididymal cysts (benign tumors on testicles)
- \_\_\_\_ Prostate problems
- \_\_\_\_ Low sperm count
- \_\_\_\_ Poor sperm quality
- \_\_\_\_ Infertility
- \_\_\_\_ Testicular cancer
- \_\_\_\_ Other cancer: \_\_\_\_\_
- \_\_\_\_ OTHER conditions: \_\_\_\_\_

## DAUGHTERS ONLY

- \_\_\_\_ Adenosis
- \_\_\_\_ Cervical anomalies (collar, ridge, hood)
- \_\_\_\_ T-shaped uterus
- \_\_\_\_ Endometriosis
- \_\_\_\_ Ovarian cysts
- \_\_\_\_ Polycystic ovarian syndrome (PCOS)
- \_\_\_\_ Pelvic inflammatory disease (PID)
- \_\_\_\_ Cystic (lumpy) breasts

**DAUGHTERS ONLY (continued)**

\_\_\_\_ Menstrual problems: \_\_\_\_\_  
\_\_\_\_  
\_\_\_\_ Premature menopause  
\_\_\_\_ Poor cervical mucus  
\_\_\_\_ Luteal phase defect  
\_\_\_\_ Fallopian tube problems  
\_\_\_\_ Do not ovulate  
\_\_\_\_ High levels of prolactin  
\_\_\_\_ Pituitary tumors (These are non-malignant.)  
\_\_\_\_ Infertility (Number of months attempted: \_\_\_\_ )  
\_\_\_\_ Ectopic pregnancy  
\_\_\_\_ Miscarriage (At what week of pregnancy: \_\_\_\_ )  
\_\_\_\_ Premature birth  
(At what week of pregnancy: \_\_\_\_ )

**DAUGHTERS ONLY (continued)**

\_\_\_\_ Dysplasia (CIN)  
\_\_\_\_ Carcinoma in situ: where? \_\_\_\_\_  
\_\_\_\_  
\_\_\_\_ Clear cell cancer: vagina  
\_\_\_\_ Clear cell cancer: cervix  
\_\_\_\_ Other cancer of vagina or cervix: \_\_\_\_\_  
\_\_\_\_  
\_\_\_\_ Breast cancer  
\_\_\_\_ Other cancer: \_\_\_\_\_  
\_\_\_\_  
\_\_\_\_ OTHER conditions: \_\_\_\_\_  
\_\_\_\_

-----  
*REMEMBER, MANY OF THE ABOVE CONDITIONS WILL NOT BE RELATED TO DES EXPOSURE.*

Has a physician ever said your illness/health condition was/is unusual (e.g. at your age or number of times)?  
If yes, please describe:

Do you know of any children of DES sons or daughters with unusual problems? \_\_\_\_\_  
If yes, please describe:

Do you have a DES-exposed sister or brother with any unusual problems? \_\_\_\_\_  
If yes, please describe:

For daughters or sons:  
If your mother is no longer living, please state cause and age of death:

Other comments (please use additional sheets if necessary):  
\_\_\_\_\_  
\_\_\_\_\_

THANK YOU FOR HELPING US WITH THIS QUESTIONNAIRE!

Adding your name and address is optional:

NAME \_\_\_\_\_

ADDRESS \_\_\_\_\_

ZIP \_\_\_\_\_

Please return this questionnaire to:

Deborah Wingard, Ph.D.  
DES ACTION Research Consultant  
Dept. of Community & Family Medicine, M-007  
University of California, San Diego  
La Jolla, CA 92093

## Book Review

*Modern Meat: Antibiotics, Hormones and the Pharmaceutical Farm,*  
by Orville Schell.  
Random House. \$17.95.

**Reviewed by Pat Cody**

Rancher and journalist Orville Schell has merged his interests and his serious concerns in a study of what happens to the meat on your table before it gets there. As a working rancher (hogs and cattle) knowing the intimate details, rhythms, and necessities of livestock production, he is in a good position to evaluate what modern technology offers. And, as a person with a broad vision, thoughtful about both short and long term effects of this bio-technology, Schell brings to his analysis a perspective not to be found at the American Pork Congress convention. Nor will it be found at the Elanco Products Co., a division of Eli Lilly (remember them?) that makes antibiotic feed additives.

Schell's book is divided into four sections: antibiotics, feed technologies, hormones, and inspection. He has learned a lot about the over-use of antibiotics as routine "prevention" in livestock feed, and writes compellingly about visits to ranchers and to scientists, to the American Cyanamid plant with its slogan "Aureomycin doesn't cost, it pays." It's hard to disagree with his thesis that over-use of antibiotics is creating drug-resistant strains of bacteria that threaten not only the health of the livestock, but also the health of those who eat meat.

## Outbreak of Food Poisoning Linked to Drugs Fed to Cattle

*N.Y. Times* 6 Sep 84

BOSTON, Sept. 5 (AP) — For the first time, doctors have traced a serious outbreak of human food poisoning to drug-resistant germs that spread to drug-resistant germs fed antibiotics to beef cattle routinely fed antibiotics to promote growth.

Critics have said that the practice of adding antibiotics to the feed of healthy animals could allow a population explosion among germs that are immune to the medicines.

In theory, resistant germs that grow in drug-fed animals could spread to humans, where they could cause diseases that could not be treated with the common and powerful antibiotics.

However, proving that this happens is difficult because of the many steps between barnyard and dinner table.

### Federal Study Traces Route

The new study, conducted by the Federal Centers for Disease Control in Atlanta, shows that such bacteria can move from farm animals into the food supply and cause grave, even fatal, illnesses in people.

"To my knowledge, this is the first time we've been able to actually demonstrate the complete sequence of events, starting with feeding animals additives and progressing through the distribution to people who became seriously ill," said Dr. Scott D. Holmberg, who directed the study.

The doctors traced an outbreak of drug-resistant salmonella infection among 18 people in four Middle West states last year to one beef herd in

phases the need for more prudent use of antimicrobials in both human and animals.

In an accompanying editorial Stuart B. Levy of Tufts Univ School of Medicine noted that until there had been no clear link between routine farm use of antibiotics and human diseases.

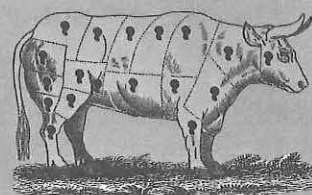
"This important missing link provided by the elegant detective work of Holmberg and colleagues wrote, 'Although only one outbreak is described, the findings are

The bacteria grew in cattle were fed the drug chlortetracycline, to a form of tetracycline, to grow faster. The bacteria were resistant to tetracycline and to penicillin, ampicillin and cephalosporins.

Most of the people who became ill had eaten hamburger contaminated with the bacteria in stores in the Minneapolis area. Other victims lived in South Dakota and North Dakota. More than 35 million pounds of hamburger is produced in each year, and about half the animals, including calves

Researcher say the broad range of microbials' systems that make have genes that make the drugs. Without these other germs, these r other spread.

Twelve of the 18 victims had taken penicillin drugs for other infections, or other treatment



# MODERN MEAT

Antibiotics, Hormones, and the Pharmaceutical Farm

## Orville Schell

Feed technologies are something most of us know very little about, but we can agree with Schell that "there is also an aspect to feeding cattle plastic hay, cardboard roughage, artificial flavors and aromas and oral insecticides that is disturbing, although it is sometimes difficult to say precisely how." The reader, however, will have no difficulty in saying how it's disturbing, when she finds these paragraphs:

In Alabama, cattlemen are turning to another inexpensive recycled feed, what is called poultry litter, which is composed of manure, feathers, and old bedding from henhouses, combined with molasses and grain to make it palatable. "It's hard to mix, it's dirty and it's smelly," Bill Beasley, an Ari-

ton, Alabama, commercial "poultry litter" retailer told a *Beef Magazine* interviewer. "But there's one thing about it . . . cows love it. We sell about all we can put together."

... But some of the most unusual experiments with recoverable resources involve feeding hogs dried sludge from sewage plants used to treat human waste. Although sludge from municipal sewage has proved to have adequate nutritional content to make it a "feasible" animal feed . . . one problem with it has so far proved insurmountable . . . there is no way to prevent highly toxic substances from building up in the sewage sludge.

Over a third of the book is devoted to  
*continued on next page*

## SUPPORT DES ACTION!

Enclosed is my tax-deductible gift. (Make checks payable to **DES Action** and mail to:  
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name \_\_\_\_\_

address \_\_\_\_\_

city/state/zip \_\_\_\_\_

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

Continued from page 7

the section on hormones. Some of it reads like a detective story: the continued use of DES as implants in cattle after it was banned, the uproar when the FDA was told (not discovered by inspection) about this, the threatening attitudes of cattlemen to reporters and to FDA inspectors. More significant, perhaps, in terms of consumer health, is the switch to other sex hormones for use as growth stimulants: Eli Lilly's Compudose (estrogen estradiol); Syntex's Synovex-S (estradiol and progesterone) are two of the many hormone implants currently in use. As Schell points out, "The market for growth-promoting hormones . . . is extremely lucrative, since an estimated 99 per cent of all commercially raised feed lot cattle are implanted." Schell visited scientists who told of their worries over the effects that hormone residues in meat may have on consumers. He concludes, "it is not so much what we already know about them but what we do not yet know about their widespread and often indiscreet use that gives cause for concern."

Pass the tofu.

## Letters to the Editor

Dear Editor:

I am outraged and frightened that the cattle and poultry industry is still using DES in the feed of their animals. The future of the people of America depends on groups like yours to lobby for the ban of DES in our food consumption. The public has to be made aware of the potential hazards of this most dangerous contamination which is not a necessary factor in these industries. . . . DES is a double threat in addition to EDB. These carcinogens have no place in our society; our future generations are being threatened.

Thank you;  
Virginia Martin  
Richboro, PA

Dear Editor:

Three weeks ago I suspected I was pregnant. Two days later my husband and I rushed to the emergency ward, where a blood test, sonogram, and culdocentesis were performed to con-

firm a (ruptured) tubal pregnancy, requiring immediate surgery . . . .

Your book, *Fertility and Pregnancy Guide* . . . was excellent throughout, but especially in the section on tubal pregnancy. Not only was it instrumental in helping me decide to go to the emergency ward, but it was thorough in after-surgery aspects. I am thankful to have it.

Sincerely,  
Peggy Kenney  
Oxnard, CA  
31 year old  
DES daughter

Dear People:

Thanks so much for your calm and informative service. It's very important to know that there's someone I can call for support and information. Your being there is an acknowledgement of this seemingly invisible wound I carry. That helps.

A subscriber  
Brooklyn,  
New York

# DES Action National

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