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# DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

Issue #27

Winter 1986

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## Health Histories of the DES-Exposed

In October, 1984, DES Action asked *Voice* subscribers and other DES-exposed people to complete a questionnaire about various health problems they may have experienced. As we stated at that time, many of the conditions listed on the questionnaire did not necessarily relate to DES exposure. With so many people exposed, we expected to see the same range of health conditions as are seen in the non-exposed population. However, we did think it very important to learn whether any health conditions—other than those already known—are affected by DES exposure. Our questionnaire was an attempt to determine whether any unusual patterns need further investigation through formal studies by scientists and medical researchers.

We present here a summary of those questionnaire results that are of particular interest. It is important to keep in mind that our group is not “typical” of DES-exposed women and men as a whole. Individuals who contact DES Action are more likely to have experienced some kind of health problem that may or may not be related to their exposure. Also, those who have had health problems are more likely to complete the questionnaire than are individuals with no problems. Therefore, questions raised by this preliminary survey *must* be pursued within a more representative, or “unbiased” group. DES Action is now working to encourage the needed follow-up studies.

DES Action mailed the health history questionnaire to 2,000 people who subscribe to the organization's newsletter, and 3,000 others who have contacted us for information, doctor-referrals, etc., but have not contributed financially. Approximately 1,700 people returned a completed questionnaire—520 mothers, 1,079 daughters and 94 sons. 80-90% said they were certain about their DES exposure (about 40% of the mothers and daughters and 20% of the sons have received medical record validation). Exposures were reported between 1941 and the late 1970s (in Mexico).

Many conditions already known, or suspected to be associated with DES exposure, were reported in high numbers on the survey. For daughters, these conditions included adenosis (48.5%), T-shaped uterus (21.5%), cervical anomalies such as hoods or ridges (48%), miscarriages (25%), ectopic pregnancies (8%), premature births (16%) and clear cell cancer of the vagina or cervix (1.5%). Some of these conditions are reported more frequently than one would expect, even from a group exposed to DES, because people who have experienced health problems are more likely to have answered the questionnaire. (For example, daughters who have had clear cell cancer are thought to be more likely to become members of DES Action. Therefore, a higher percentage would have answered the questionnaire.) For sons, conditions frequently reported include undescended testicles (18%), epididymal cysts (13%), low sperm count (21%) and poor sperm quality (13%). Eight percent of the mothers reported breast cancer.

Some conditions that are not, at present, known to be related to DES exposure were reported more frequently than expected. For example, the number of reported colds, flu and respiratory conditions during the past year in daughters and sons was twice as high as the number reported for comparable age and sex groups in a national survey of the general population (the 1979 National Health Information Survey—NHIS). These results of our survey point to a need, therefore, for further study of the rate of infectious illness in women and men exposed to DES before birth.

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## 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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## How Priorities Are Set

by Kim Klein

Probably the most serious and well-publicized epidemic to strike the United States recently is AIDS. AIDS, Acquired Immune Deficiency Syndrome, is a disease causing total breakdown of the immune system, and in almost every case causes death. With so much media attention focused on the disease (especially after Rock Hudson died of AIDS), it has surprised many people that drug companies are not rushing to research cures for the deadly and mysterious condition.

We now have an explanation: A vice-president of one of the largest pharmaceutical companies in the country explains that, to the pharmaceutical industry, AIDS is small potatoes. In an interview with the Los Angeles Times, L. Patrick Gage, of Hoffman-LaRoche commented, "You have to understand that 1,000,000 people (one estimate for the number of people affected by AIDS-related conditions in the United States) isn't a market that's exciting. Sure, it's growing, but it's not asthma or rheumatoid arthritis."

Unfortunately, this is the same rationale we have heard from government officials to excuse the lack of funding for DES-related research: there are so many more people suffering from other conditions. I can't help but wonder what would happen if health care research had the almost limitless funding of the Pentagon!



The *DES Action Voice* is published quarterly by DES Action USA, Inc.  
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# Film Reviews

**The Ultimate Test Animal.** Produced by independent journalists Karen Branan and Bill Turnley. 40 minutes. Available in VHS, Beta, and  $\frac{3}{4}$ ". Purchase: \$125. Rental: \$60. Contact: Karen Branan, 3231 14th Avenue South, Minneapolis, MN 55407.

*Reviewed by Kari Christianson*

*The Ultimate Test Animal*, a new video documentary by independent producers Karen Branan and Bill Turnley of Minnesota, tells the alarming story of the use of the drug Depo-Provera as a birth control method. Depo-Provera, a synthetic form of progesterone developed by the Upjohn Company, is being used as a potent contraceptive given by injection at three-month intervals. While Depo-Provera has been widely used for contraception (as well as for other uses) in this country and in others for over 20 years, the U.S. Food and Drug Administration has never approved this drug for use as a birth control injection.

This documentary addresses the controversy surrounding use of this synthetic hormone and takes the viewer inside the January, 1983, FDA Public Board of Inquiry hearings in Washington, D.C., where testimony was provided for and against the use of Depo-Provera as a contraceptive. In health centers, women's homes and refugee camps, as well as the hearings, women who received Depo-Provera share the dramatic effects of the drug on their health. These side effects include headaches, depression, weight gain, loss of sex drive and blood clots. Several women had developed cervical cancer.

Spokespeople for the Upjohn Company derided the reliability of animal studies to determine drug safety. Indeed, the title, "The Ultimate Test Animal" must have occurred to the producers after hearing one physician claim the "final animal model" for determining the safety of a drug to be used by humans would be the human being. This is a common argument by drug companies. In the case of Depo-Provera, as with DES, "final" means exposed—the

damage has been done. Against the drug company's declaration that Depo-Provera is safe stands the statement by Fletcher Campbell of the FDA that "animal data is more worrisome for this drug than for any drug that we know of that is to be given to *well* people." (emphasis in original)

While the FDA's Public Board of Inquiry ruled in October, 1984, not to approve Depo-Provera as a contraceptive, the Upjohn Company continues its troubling quest for FDA approval. (In a recent conversation, producer Karen Branan expressed concern that Canada is on the verge of approval.) And, the drug is still readily available for contraceptive use in the U.S. and other countries.

This enlightening documentary on an important women's health issue offers a primer on Depo-Provera and its hazards as a contraceptive. Millions of women worldwide—the majority poor and of color—have received "The Shot." The film raises disturbing questions about racism and sexism in health care; population control versus birth control; and how drugs are tested and marketed. Unfortunately, it seems that lessons on hormones are learned very slowly and often too late. *The Ultimate Test Animal* should be mandatory viewing for all those grappling with consumer education regarding synthetic hormones.

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**DES: An Uncertain Legacy.** Directed by Bonnie Andrukaitis. Produced by Studio D, National Film Board of Canada (NFB). 1985. 58 minutes. Available in VHS, Beta,  $\frac{3}{4}$ " and 16mm. Contact: NFB, P.O. Box 6100, Montreal, Quebec, H3C 3H5, Canada.

*Reviewed by Mary Louise Adams*

In 1982, filmmaker Bonnie Andrukaitis heard an interview with Harriet Simand, founder of DES Action/Canada, on a Montreal radio station. A DES daughter herself, she contacted Simand for more information. After attending several meetings of DES Action, Andrukaitis realized the scope of medical problems surrounding the drug and set out to make a film.

The result, *DES: An Uncertain Legacy*, is a well-researched and comprehensive film intended to serve the general public. Produced by Studio D, the women's studio of the National Film Board of Canada (NFB), it has the benefit of an adequate promotional budget and a wide distribution network. As part of the NFB library, it is now available around the world to television stations, groups and individuals (free within Canada).

Much of the film is devoted to piecing together the story of Harriet Simand. We follow her from interview to interview, from local radio shows to national television broadcasts, where she speaks frankly of the effect DES has had on her life and on the lives of other young women. As a cancer daughter, Simand first went to the media in an effort to bring DES to the attention of both the government and the general public. Doctors had been trying to tell her that DES wasn't widely used in Canada, that it was "mostly a problem in the States." After a front page story in the *Montreal Gazette* and coverage in the city's French press, Harriet and her mother Shirley Simand received 2,000 calls, which, says Harriet, "seems like a lot of people to be interested in a drug that was 'hardly ever used'."

In the film's most candid and compassionate sequences, Harriet's mother tells of her experiences both during pregnancy and after learning of her daughter's cancer. After years of trying to conceive, she was prescribed "pills and injections" during two eventual pregnancies. Ironically, the first ended in miscarriage. Happily, the second, under the same conditions, ended with Harriet.

The film is very much a testimonial to Harriet and Shirley Simand, to the sheer amount of work they have done to bring DES to the public consciousness, to the fact that two determined women can do enough, can rally enough support, to make change. However, in focusing on Harriet and later on an American, Joyce Bichler (another cancer daughter who was successful in a lawsuit against the Eli Lilly Company), the film leaves its audience with a very strong message that DES leads to cancer. Although a DES daughter with fertility problems and her husband, a DES son, are also interviewed, we don't really

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## Health Histories *continued...*

### Number of Respiratory Conditions/100 Persons Per Year

DES Exposed		National Health Information Survey	
DES daughters	255	NHIS women, 17-44 years	124
DES sons	207	NHIS men, 17-44 years	98
DES mothers	130	NHIS women, all ages	117

People answering our questionnaire also reported apparently higher percentages of asthma, arthritis and lupus, compared with the general NHIS population (see

below). The number of lupus cases, however, were so few (8 daughters and 5 mothers), that the result is difficult to interpret.

### Percentages of Asthma, Arthritis and Lupus Reported

DES Exposed		National Health Information Survey	
		Asthma	
DES daughters	9.6%	NHIS women, 17-44 years	2.6%
DES sons	14.9%	NHIS men, 17-44 years	2.2%
		Arthritis	
DES daughters	7.8%	NHIS women, 17-44 years	5.8%
DES sons	8.5%	NHIS men, 17-44 years	3.7%
		Lupus	
DES daughters	0.7%	General population, all ages	0.002%
DES mothers	1.0%	General population, all ages	0.002%

Other conditions that were reported in our questionnaire answers and that seemed to need further evaluation for daughters include pituitary tumors—generally not malignant—(0.6% compared with 0.007% in women 15-44 years in the general population), high prolactin levels (high levels of the hormone, prolactin, as measured through blood testing), and premature menopause (cessation of menstrual periods significantly earlier than expected). For sons, such conditions include prostate problems (14.9% compared with 0.5% in males 17-44 years in the NHIS).

Remember that while many of these conditions seem to occur much more frequently in the DES exposed, we cannot

draw any conclusions from our survey, due to the self-chosen nature of the group of individuals who participated. We are still examining the responses for certain other conditions included in our questionnaire and do not yet know whether rates among our group are higher than expected. As further information becomes available, we will report it to you.

Our thanks to Dr. Deborah Wingard and her students at the University of California, San Diego, the epidemiologists who worked with us in developing this survey and who compiled the questionnaire results. And, of course, our thanks to all of you who provided such valuable information to us by completing our questionnaire.

## Film Review *continued...*

see the scope of the more commonplace health problems caused by the drug.

Commendably, Andrukaitis places the development of the "miracle drug" in the context of post-war North America. Consumerism was the prevailing ideology as women were pushed out of their wartime occupations back into the home where they were to raise happy, healthy children. As the economy skyrocketed and homes became affordable, the baby boom began. The film's narrator tells us that "a miscarriage could shatter that dream." It could also leave a woman with the option of entering the workforce, of circumscribing her socially prescribed role. Enter DES.

Andrukaitis offers little analysis of DES as a consequence of women's oppression. We come to understand that its production was due, in part, to profit-hungry drug companies and to an elite and self-aggrandizing medical profession. But we miss discussion of how both the pharmaceutical and medical industries set their priorities. How has pregnancy come to be seen as an event requiring medical intervention? How is it that women have value in this society only as they fulfill the role of wife and mother?

In not addressing such questions, the film neglects to situate DES Action within the broader feminist health movement. As Margaret Trudeau says in one of the interview clips with Harriet, "Well, certainly, if it is affecting the sons and the males of our species, the government will probably do something about it."

*DES: An Uncertain Legacy* lacks nothing in the way of concrete information. As a catalyst to discussion, it is a valuable tool. The stories of Harriet Simand, her mother Shirley, Joyce Bichler and the others can give women a sense of their own power to not only take control of their health, but to make change in the world. In so doing, they will no doubt develop the feminist analysis the film is missing.

*Mary Louise Adams is a feminist writer and editor who lives in Toronto. She writes frequently on issues of women's health and was one of the first to write about DES in the Canadian press.*

# Warning on Menopausal Estrogen

Women who take estrogens such as Premarin (a "conjugated estrogen") have an increased risk for uterine cancer, according to a major study published in the New England Journal of Medicine on October 17, 1985. In a group of 425 women with endometrial cancer who were interviewed for the study, 31% had used conjugated estrogens beginning at least two years before the interview. By comparison, less than half—15%—of a control group (those of a similar age who did not have cancer) had used such drugs. The women studied ranged in age from 50 to 69.

In describing the significance of their study, the authors note that:

"...long term use of conjugated estrogens increases the risk of adenocarcinoma of the endometrium [ed. note: uterine lining], regardless of the stage of disease, and...the risk remains elevated for many years after cessation of use. ...Our results do not accord

*"Long term use of conjugated estrogen increases the risk of adenocarcinoma of the endometrium..."*

with the suggestion that the risk of endometrial cancer declines soon after the discontinuation of estrogen use. ...Our findings have public health implications, since they suggest that the risk of localized and extensive endometrial cancer is increased with the use of conjugated estrogens, both while the drug is being taken and for an indefinite period after it is discontinued. All

women who have not had hysterectomies who have used estrogen for a year or more should be considered for long-term gynecologic surveillance, regardless of when the drug was last used..."

DES Action would add that this report does not address whether or not *any* further estrogens are advisable for DES-exposed mothers or daughters. The Federal DES Task Force 1978 Report stated, in reference to DES mothers, "The use of post-menopausal or peri-menopausal replacement estrogens should be discouraged." It also said, referring to DES daughters, that "oral contraceptives and other estrogens should be avoided." Many women use non-medical ways to relieve menopausal symptoms. See our review of the book, *Menopause, Naturally*, by Sadja Greenwood, M.D., in *Voice* Issue #25, Summer 1985 (or order this back issue from us for \$2.00).

## Major Settlements in Michigan

In the largest mass settlement of DES legal cases to date, Michigan court officials announced on October 29, 1985, that 240 DES daughter cases within the state of Michigan had been settled. The individual cases, which had been accumulating since 1974, were all settled out of court for undisclosed amounts of money.

The court-approved settlements were announced by Wayne County (Michigan) Circuit Court officials, but a judicial order kept the settlement amounts and other details secret. One of the judges monitoring the negotiations, Judge James E. Mies, commented that this is apparently the largest mass settlement for the court. Of particular note is that seven of the 240 plaintiffs had had clear cell cancer. The other 233 plaintiffs suffered from a variety of health problems known to be caused by DES exposure, such as cervical and vaginal abnormalities and pregnancy problems.



Lawrence Charfoos was attorney for the DES plaintiffs. Lane Bauer was lead counsel for Eli Lilly and Co., one of the major defendants. The other defendants were Abbott Laboratories, the Blue Line Co., Burroughs Wellcome Co., Central Pharmaceutical Co., Cole Pharmaceutical Co., Kremers-Urban Co., McNeil Labo-

ratories, Merck, Sharpe & Dohme, Rexall Drug Co., William J. Rorer Inc., S.J. Tutag & Co., Schering Corp., E.R. Squibb and Sons, Upjohn Co., and Vale Chemical Co. The settlement did not involve an admission of guilt by the 16 drug company defendants.

In 1984, the Michigan Supreme Court ruled that the DES plaintiffs could sue even if they could not identify which manufacturer supplied the drug that their mothers had taken. Attorney Charfoos was quoted as saying, "That ruling changed the law in our most populated states to enable consumers to have their day in court and obtain compensation for injuries caused by exposure to toxic substances such as DES."

Approximately 25 DES cases brought by other lawyers are still on file with the Michigan court, and hundreds more are pending in courts across the country.

# DES Action 1985 Annual Conference

DES Action members gathered at a retreat center outside Boston from October 25-27, 1985, for an annual conference that saw the largest attendance in the organization's history. More than 70 women and men from 32 DES Action groups located in 16 states and five Canadian provinces met to plan activities for the coming year and share experiences and ideas. In an exhilarating and educational weekend, hosted by DES Action's Boston chapter, members focused on DES Awareness Week scheduled for April 20-26, 1986. This year, DES Awareness Week will inform the public and health professionals about issues related to DES exposure and reproduction, including infertility, high risk pregnancy, and the basic question of whether or not to parent.

Nancy Adess, Pat Cody, Kim Klein and Harriet Simand opened the conference with an exciting report, including slides, of the World Women's Conference in Kenya in July, 1985, where they represented DES Action.

Nancy Adess, outgoing Executive Director, was presented with a beautiful quilt handmade by DES Action locals and assembled by Vickie Dandridge of the San



Nancy Adess

Diego chapter. Eileen Hansen was introduced as the organization's new national Executive Director (see article on page 8).

Workshops and discussions focused on topics such as Current Medical Practices, Infertility Counseling, Reproductive Technologies, Reading the Medical Literature, Fundraising, Litigation and Legislative Updates, DES Cancer Network, Canadian News, DES Sons, and Use of Personal Computers for DES Action Work. Conference goers were also treated to the recently released film, *D.E.S.: An Uncertain Legacy*, produced by the National Film Board of Canada (reviewed in this issue).



## Donate to DES Action!

It's not too late! There is still time to donate to DES Action through the United Way appeal. DES Action welcomes contributions either directly to us, or through the United Way's Donor Option Plan, at any time of the year. DES Action USA and its local chapters are not United Way agencies and affiliates, but as a health organization, DES Action is able to participate in this Donor Option Plan. United Way campaigns are independently

run in each state, with September-December generally the major focus of the campaign. However, pledges are accepted after that time. Check with your local United Way to determine what procedure for giving is used in your state. Please let us know if you designate us as your United Way pledge recipient, so we can mark our records. DES Action appreciates your support. Please give generously **today!**



## DES ACTION USA

DES Action USA announces its new name (changed from DES Action National). This name change helps distinguish the United States organization from our growing family of DES Action organizations in Canada, the Netherlands and Australia.



## Letters to the Editor

We received a number of responses to the letter from "C.C." in New York, which appeared in Issue #25, Summer 1985. Here are excerpts from several of them.

Dear C.C.:

...I am a DES daughter. When I was 22, I went through a cone biopsy because I had cancer in situ (non-invasive cancer of the cervix). At that time in my life, my live-in boyfriend was extremely supportive. He stayed by me late into the night during my stay in the hospital. That brought us even closer.

Since that time, I have dated many men and have never been dumped or experienced rejection in a relationship because of a DES condition. Nor do I know of others who have experienced rejection because of a DES condition, and I know a few ladies who have had some DES complications.

If you are going through a DES crisis, tell whomever you want. Talk about it as you would any other subject that affects your everyday life. I get nervous when I have a doctor's appointment for my checkups, so I'll mention it to my friends, co-worker or my mom—and they'll be concerned for me. That makes me feel better...

S.A.  
New York

friend (boy/girl) is when you do, in fact, have a relationship—when you are getting close.

An example is my own experience. I did not tell my husband about my DES exposure until he wanted to date me exclusively. In other words, we were making a commitment. I was so glad I told him because later, I did have some problems.

It's better to find out early if your partner is going to run out or stand by you if problems arise. If your partner is shallow enough to dump or shun you, then they are definitely not worth your time!

Liz  
California

Dear C.C.:

...I am writing as the male partner of a woman exposed to DES. I met "V" through my cousin and within minutes we became curious about each other. As we spent time getting to know one another, I realized I wanted to maintain lines of communication between the two different cities in which we live.

"V" and I proceeded to subsidize the airwaves, hungry to learn more and more about each other. She was so precious in relating to me her experiences with DES, cancer, surgery, radiation, and cancer and surgery again; and if that wasn't enough, her legal and emotional struggle with the drug companies. It seemed that with each call, "V" risked revealing another part of her whole DES nightmare with me. The more she risked, the more I risked, and our trust grew, and with it our feelings. I surprised myself by saying, "You know, I really want to say 'I love you'." We began to fervently long for each other and it was not long before "V" offered to visit me.

When "V" stepped off the plane, I saw this radiant soul of happiness and embraced her healing energy. Rather than choose to be a body ravaged by disease, she exuded something infinitely more appealing and powerful—her will to give and receive love.

"V" and I have since created being together quite a bit, and we continue to grow each day. What else is there? Oh, since you're probably wondering, she is a wonderful partner—in all ways!

Dave  
Texas



Dear C.C.:

...I believe the best time to tell your

## 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)

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- ☐ Supporter: over \$250

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Receives the *Voice* plus *DES: The Complete Story* by Cynthia Orenberg.  
Receives all of the above plus annual reports on the organization's progress.

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ADDRESS \_\_\_\_\_

CITY/STATE/ZIP \_\_\_\_\_

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

# DES Action

## Welcomes New National Executive Director

DES Action USA is pleased to announce the selection of our new national Executive Director, Ms. Eileen Hansen. (Nancy Adess, founding member and former Executive Director, resigned to develop her own business as an editor and writing consultant. She will continue her work with DES Action as a member of the Board of Directors.)

Eileen comes to DES Action with a long history of involvement in women's issues, including health-related concerns; in administration of human service organizations; and in the training of community organizers. She accepted the position in San Francisco upon moving from Boston, where she was Director of Planning and Development for the Quincy School Community Council, the Northeast's largest non-medical, multi-



Eileen Hansen

service center providing a variety of human services to Southeast Asian refugees and Chinese immigrants.

Eileen has long been concerned about the use of DES, as well as the enormity of dangerous toxins distributed through our air, food, land and water without our consent. "I am delighted to accept this position as Director of a vital, growing grass roots organization, as I am convinced that action on the issues of our day does not occur unless people band together to demand change." Eileen further stated, "DES is certainly one such important issue and DES Action is exactly the kind of organization that can effect policy change in the future—not only in the United States, but throughout the world."

Welcome, Eileen, to DES Action!

## DES Action USA

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