DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

Issue #26 Fall 1985

DES Action Hosts Second Research Conference

In June, 1, 1985, DES Action co-hosted a Conference on DES-related research. Held at the University of California, Berkeley, the Conference was organized by DES Action's Research Liaison, Judy Turiel, and DES Action member Deborah Wingard, an epidemiologist at the University of California, San Diego. With primary funding from the University's Cancer Research Coordinating Committee, and supplemental support from the Henry J. Kaiser Family Foundation, we were able to invite experimental scientists, clinical medical researchers, and epidemiologists from Canada, Sweden, and throughout the United States.

The one and one-half day Conference expanded upon a smaller meeting convened by DES Action in 1983. The June conference this year provided a unique opportunity for researchers from diverse scientific disciplines and medical specialties to discuss recent studies and future research directions. New collaborations among some of the participants to study unanswered questions about DES exposure may well develop out of this gathering.

Among the major points emphasized during presentations and discussions are the following:

1. **Financial support is needed** for consistent, long term follow up research that will consider a broad range of *possible* DES effects as the population grows older. If additional health problems exist, they can be detected early; reassurance can be gained if no new problems appear. It is imperative that the major existing human study samples are maintained in order to allow adequate research involving mothers, daughters, and sons. These study populations are from the University of Chicago's 1950s study and the DESAD Project study, funded by the National Cancer Institute from 1973-1981.

2. **Studies of DES sons** remain inadequate and conflicting. More research is needed to determine whether sons show increased rates, or unusual types, of testicular cancer. Studies in mice suggest the need to monitor for possible prostate problems.

Dr. Robert Stillman talking with DES Action National Board members Joan Emery and Pat Cody

3. As published last year in the *New England Journal of Medicine*, **DES mothers** have a moderately increased risk of breast cancer (approximately 40% greater risk than women not exposed) and need to obtain careful, regular, professional screening.

4. **DES daughters and their health care providers** need to be aware that certain medical procedures should *not* be routinely done; weighing of risks and benefits must always include the special circumstances of DES exposure:

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INSIDE:

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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Dear Doctor

Thanks to **Dr. Arthur Haney** *for answering our Dear Doctor question. Dr. Haney is Director of Reproductive Endocrinology and Infertility at Duke University Medical Center, Durham, North Carolina.*

Q. Several months ago I had a laparoscopy and was found to have endometriosis. My doctor gave me the options of attempting pregnancy right now, having a hysterectomy, or taking a male hormone, Danazol. While I don't want to get pregnant immediately, or lose my fertility, I'm concerned about Danazol's side effects. I went to another physician and got a second opinion and he told me to take a low dose oral contraceptive pill, Ovral. I took the Ovral, but it gives me extreme mood swings. I've also noticed some pain in the pelvis which makes me think the endometriosis might be active. Do I have any other options?

A. I don't think it's a particularly good idea to delay attempts at child bearing once you know you've got the disease, if the social circumstances permit. However, if you wish to delay starting a family, let's look at your options. For someone who wants to preserve fertility and does not have a substantial amount of endometriosis involvement of the other pelvic structures, a hysterectomy is very extreme. There should be no problem with suppressing the disease for maintenance of reproduction at a future date.

The drugs they use to treat endometriosis mirror those natural circumstances when endometriosis either does not occur or regresses. These include pregnancy, anovulation (lack of ovulation), and menopause. Pregnancy can be mimicked by continuous use of oral contraceptives.

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DES Action Now International

Our message about DES—its use and its consequences—was brought to the United Nations Decade for Women Conference in Nairobi, Kenya in July. Thanks to funding, in part, from the Skaggs Foundation of California, Pat Cody, whose work for DES Action includes International Liaison, attended the Non-Governmental Organizations (NGO) Conference together with Executive Director Nancy Adess and Board member Kim Klein (who paid their own way). They were joined by Harriet Simand of DES Action Canada and Anita Direcks and Ellen 't Hoen of DES Aktiegroep, the Netherlands, in 10 days of outreach, press conferences, and workshops.

"We were dismayed to learn," reports Nancy, "not only that DES has been used in most countries, but that it is *still* being used for pregnancy maintenance in many nations, including Mexico, Brasil, Costa Rica, Peru, Rwanda, Zaire, and Kenya." Our DES Action team found that this is just one example of the use and abuse of drugs in developing nations that lack the money to do their own research on safe and effective medications. Indeed, a doctor from a major Kenyan hospital reported that their problems include having to use out-dated antibiotics sold by unscrupulous middlemen. DES Action worked with the Network on Pharmaceuticals (WEMOS—see accompanying article, page 6) in having the official United Nations Conference meeting in Nairobi at the same time adopt a resolution against ineffective and dangerous drugs.

The three DES Action groups decided to form DES Action International in order to publicize the DES story in other countries. Our first action was to ask for a world-wide ban on DES by governments throughout the world. In making this recommendation to the official UN Conference we stated, "only when DES is removed from production can we be assured that it will no longer be used in this dangerous fashion [during pregnancy]."

At a workshop building an international women's health network, DES Action gave a report to women from many nations who will now find out about DES use in their countries, using the materials we provided for public education.

DES Action International set up a display of DES leaflets in Arabic, Swahili, French, Spanish, English and Dutch on the campus lawn which was the central meeting place of the Conference. There we talked every day with hundreds of women attending the conference from all over the world. Journalists from television, radio, newspapers, and magazines interviewed members of our group. Coverage included:

- *TV*: Cable News Network (CNN) from the U.S.
- *Radio*: Voice of America, Irish, Finnish, Spanish, Danish, German, Norwegian, Swedish, Dutch, Cuban, and Canadian radio systems

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Research Meeting *continued...*

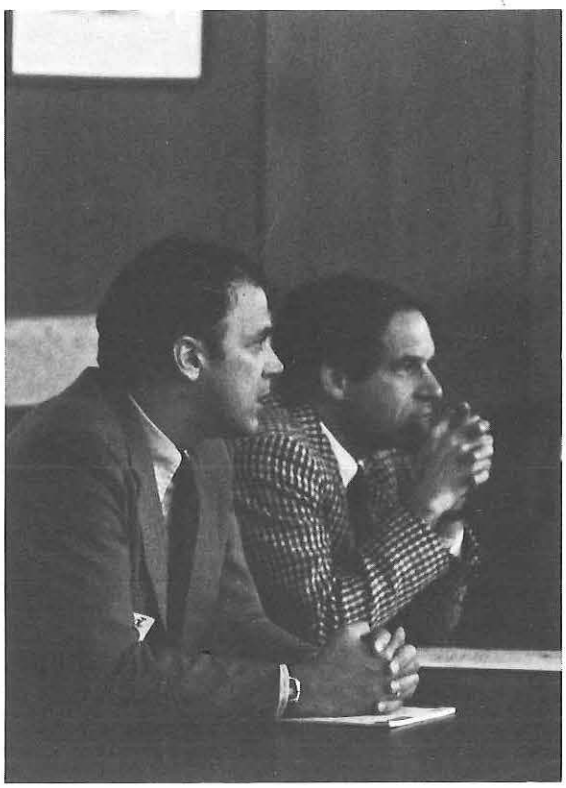
- *Cryosurgery* and other procedures on the cervix result in greater complications (especially narrowing and scarring of the cervix) among DES daughters. Although DES daughters are now known to have increased rates of cervical dysplasia, the common treatment by cryosurgery is not always needed. In many cases, careful observation over time to see that the dysplasia does not become more severe will be enough.
- *Routine hysterosalpingogram* (or HSG—an x-ray of the uterus and Fallopian tubes) is *not* suggested, as it cannot accurately predict pregnancy outcome. HSG should be considered as part of an infertility "work-up," only according to the individual woman's case.
- *Cervical cerclage* (stitching the cervix shut) should *not* be routinely performed to prevent late pregnancy loss. (Only about one-third of preterm deliveries appear to be related to "cervical incompetence.") Tocolytic medications to stop preterm labor contractions have been effective in DES daughters.

5. **Pregnancy loss in DES daughters** does not appear to be repetitive *if* appropriate "high risk" prenatal care is given; most DES daughters will be able to successfully deliver a healthy infant.

6. **There are no good studies of fertility or the endocrine system** in DES daughters or sons. Studies in some genetic strains of mice have raised questions about possible immune system effects in some DES sons and daughters. Given the complexity of the immune system, it is not clear what such "effects" would "look like" in humans; however, studies of infectious disease, auto-immune conditions, allergies, as well as cancer-development, should be undertaken.

8. Finally, Conference participants agreed that **DES Action should continue** in its role as a liaison among researchers from various fields and locales, since these individuals do not otherwise communicate with each other. Participants urged DES Action to convene similar meetings, perhaps every two years, if funding can be found.

Needless to say, DES Action looks forward to continuing this effort, and appreciates the support from Conference participants, the funding sources and, of course, our membership.



Dr. John McLachlan (left) and Dr. Stanley Robboy

Dear Doctor *continued*

This suppresses the disease and atrophies it comparable to what happens during pregnancy. It does carry some side effects as you've noted and has some life threatening problems associated such as vascular accidents, hypertension, etc.

Danazol is an attempt to create a state of anovulation. Unfortunately, the compound is a derivative of testosterone and it has some testosterone-like activity. It is also very expensive. The efficacy with Danazol is less clear than with other medications and it has recently been noted that the compound does not really create a state of low estrogen. It does provide very good symptomatic relief. For the above reasons, however, the use of Danazol has diminished.

Another compound, Medroxy—Progesterone Acetate, has been found to be very useful. This is essentially the Progestin part of the oral contraceptive tablet without the toxic effects of estrogen. It suppresses the pituitary and stops ovarian function analagous to menopause. The lining of the uterus, whether it's in the appropriate place within the uterus, or outside the uterus (i.e. endometriosis) regresses; typically the patient has a marked improvement in her symptoms. The main side effect is erratic vaginal bleeding which takes place for several months upon initiation of the drug. Some spotting may also occur and occasionally patients are depressed. All in all it has far fewer side effects than Danazol, with the majority of side effects being simply the annoyance of erratic bleeding. Once you have been treated with Medroxy-Progesterone Acetate it's then reasonable to consider standard cyclic oral contraceptive use. Endometriosis rarely progresses on oral contraceptives, so at least it maintains the status quo with regard to the disease.

Thinking of Adoption? Some Guidelines to Get You Started

By Joyce Bichler and Andrea Goldstein

Although most men and women who are DES-exposed *will* be able to father or give birth to a child, some are faced with infertility, cancer, repeated miscarriages and ectopic pregnancies. These people must seek other options if they wish to start or increase their family size.

The following are some general guidelines for those who are considering adoption:

1) Before taking any action, the individual or couple must come to terms with their feelings regarding their infertility (if this is the reason for turning to adoption). For some, seeking an adoptive child is an acknowledgement that a successful pregnancy is unattainable. Although adoption does not rule out a pregnancy it does mean that energies and efforts will be focused on bringing a child into the family through legal rather than biological means. This switch in focus can bring up feelings of inadequacy or failure.

Often, one member of the couple is reluctant to consider adoption. These feelings may stem from misinformation and/or misconceptions about adoption. Sometimes the person is reacting to internal or family expectations that they should only have their "own" child. It is important that the couple identify and discuss these feelings. It is often helpful to talk to others who have adopted and ask them the questions that you may be wondering about. Adoption agencies frequently offer informational meetings to people who are thinking about adoption. Attending such a meeting is not a commitment to adopt. It is a way of getting good information and provides an opportunity to share feelings with others.

2) Once the adoption route is agreed upon there are several questions that the potential adoptive parents must try to answer honestly for themselves. Remember that there are no "right" answers nor any "shoulds" that apply:

What kind of child would you be willing to accept?

- a healthy infant?
- an older child?
- a physically handicapped child?
- an emotionally handicapped child?
- a foreign born child?
- a child whose race or birth religion is different from yours?
- a sibling group of two or more children?

· How much money can you realistically afford to spend on the adoptive process? For example, surrogate parenting may be a desired option but the cost may be prohibitive.

· How long do you want to wait for a child?

3) Next it is important to contact an attorney who is knowledgeable about adoptions in the state in which you live. To get referrals to lawyers, talk to people who have adopted, call the American Bar Association, call local adoption agencies, or look in the telephone book under Adoption. An attorney will discuss the different types of adoption that are available to you in your state. With adoption laws varying widely from state to state it is crucial to have accurate information on what constitutes a legal adoption in your state. A lawyer will also inform you of the costs of different adoption options.

"It's often helpful to talk to others who have adopted..."

Contact RESOLVE, a group that deals with issues regarding infertility. They put out a booklet on adoption and can be a good source of information.

4) Next, depending on your state laws you may decide to employ two or three different methods of seeking a child, such as:

1) Contacting state adoption agencies. Going through a state agency is usually your best option financially, but you may not be interested in the type of child they usually have available (for example, state agencies usually have very few healthy Caucasian infants).

2) Adopting a foreign born child through public or private agencies. Children are available from various countries such as Peru, Korea, Colombia, to name just a few. Beware of individuals who promise quick and easy adoptions from foreign countries. Sometimes they fail to live up to their promises. You have more protection if you stay with the larger licensed agencies that have experience with foreign adoptions. They are better able to deal with the paperwork and bureaucracy involved and often the children are healthier.

3) Directly advertising for a child. Your lawyer will know the best places to place advertisements if this is legal in your state.

4) Open adoption—where the surrendering parent retains visiting rights. Again, discuss this with your lawyer.

4) If private adoption is legal in your state you can notify ob-gyns and pediatricians in your area that you are seeking a child (in fact, let *everyone* know). Once a child who needs a home is identified for you, you must go through the courts to legally adopt the child.

Each state has a different waiting period before an adoption is finalized. Again, your agency or lawyer will know the law in your state.

If you'd like more general information regarding adoption or if you've already adopted and have information you'd like to share with others, contact Andrea Goldstein, DES Action, Boston, P.O. Box 126, Stoughton, MA 02072.

Good luck!

Resources: RESOLVE, Inc., P.O. Box 474, Belmont, MA 02178

Martin, Cynthia D., *Beating the Adoption Game,* Oak Tree Press.

WEMOS: International Network on Pharmaceuticals

Networking—that great institution of the 80s—was of course a major activity at the World Women's Conference in Nairobi last July. DES Action National joined in and used our attendance at the Conference to link up with other health action groups. These included a newly developing Latin American Women's Health Network forming under the auspices of the International Feminist Network, ISIS; the International Organization of Consumers Unions (IOCU); our own U.S. National Women's Health Network; and an international health network called Health Action International (HAI).

HAI provides an international link for organizations working on a variety of health issues. One of the most prominent of these groups at the Conference was WEMOS, an international women's network on pharmaceuticals. We were, naturally, particularly interested in what WEMOS is doing.

Because WEMOS is based in the Netherlands, our Dutch DES Action affiliate has provided them with much information on the use and effects of DES. As a result, WEMOS literature and educational efforts throughout the world use the DES story as one example of unsafe and ineffective pharmaceuticals marketed for women.

The main aims of the WEMOS Network on Pharmaceuticals are to produce information for women all over the world about possible health risks associated with various prescription drugs, to stimulate research and production of non-drug solutions in the areas of contraception and abortion, and to stimulate research and production on male contraception.

One primary WEMOS concern is to educate women about the dangers of high dose estrogen-progesterone (EP) drugs. These drugs have been used as a pregnancy test, as treatment for missed periods, and to induce abortion. Because the use of high dose EP drugs is dangerous, they have been banned in Sweden, Finland, the United States, Singapore, and the United Kingdom. Nevertheless, they are still in use, particularly in third world countries. In every instance, EP drugs are either ineffective or unreliable, unsafe for the woman and, especially if she is indeed pregnant when using them, unsafe for the fetus.

Because people in the Third World, and especially women, have little access to specialized information on drugs, WEMOS has produced informational leaflets and made them available in English, French, Spanish, Arabic, and Kiswahili. These leaflets cover the topics of oral contraceptive pills, IUDs, the diaphragm, high dose estrogen-progesterone drugs, and DES.

Forging links with WEMOS, HAI, and other international health action groups will help DES Action to educate the millions of women throughout the world who have been given—or are still being given—DES during pregnancy.

International *continued...*

- *Magazines*: from Egypt, the Netherlands, Japan, and the U.S.

To give the flavor of the meeting, here is a paragraph from the *Los Angeles Times* of July 19:

> "The campus lawn is spotted with clusters of women literally hawking their causes and issues, spreading posters and pamphlets in circles around them—'Imprisoned Ukrainian Women' halfway across the lawn from 'Iranian Women and Islam.' A few feet from 'Islam and Women,' where American Black Muslims were speaking, 'DES, The Wonder Drug You Should Wonder About' was on one side of a portable billboard, while behind it a Japanese woman knelt among tiny paper cranes as she spread out a banner against nuclear war."

It was an exciting place to be for 10 days in July, and an important starting point for DES Action International.

Letters to the Editor

This is in response to "CC" from New York's letter in the Summer '85 issue.

Dear CC:

Please don't worry about being "dumped," "shunned" or ignored because of your DES condition. There is nothing to be ashamed of. Remember that when your mother was carrying you, she and her doctor believed that taking DES was in *your* best interest.

I, too, am exposed and show many of the typical effects of the drug. I am very open about my condition, and have never been "dumped," "shunned" or ignored because of it. On the contrary, I have always met with understanding and sympathy from both male and female friends.

My advice to you is to be straightforward, open, and most of all, *educated* about your condition. When you feel close and comfortable enough with your friend, discuss it openly. In no way does your friend's knowledge that you are DES exposed detract from your qualities that attract your friends.

Sincerely,
AH
California

Dear Editor:

Perhaps, in addition to your service to mothers and DES children, you will be able to influence—and effect change—among those physicians who deny patients ready and complete access to medical information.

I am on your mailing list only because of longstanding fear.

The obstetrician who treated me for early spotting complications during my 1961 pregnancy dispensed some kind of hormonal medication in his office. But I never knew what it was. Several years later, when DES was publicized, this obstetrician told my family physician that he did not keep records of patients for more than five years and could no longer remember what he might have given me in 1961.

Two years ago I wrote to this obstetrician, specifically requesting my records, after DES Action information led me to believe this information was available to any patient. He telephoned me to say that my records had somehow disappeared. This obstetrician is the chief of an ob-gyn division in a large metropolitan hospital.

At that time I also wrote to the hospital where my son was born. They ignored my request for my hospital records until I wrote a second letter to the hospital director. The barely legible xerox I received concerned only the labor and delivery; the space provided for prenatal information omitted my prenatal history.

Late in 1983, through DES Action, I was given the name of a practicing obstetrician in another part of this city. He took the time to listen to what I could recall of that pregnancy, and reassured me that I had not been given DES. He said doctors today are too afraid of malpractice suits to give out *any* information.

I remain grateful to DES Action for easing my long concern.

Sincerely yours,
A subscriber
Ohio

N.Y. Study Seeks DES Sons

Loren W. Green, M.D. is beginning a study of pituitary hormone function in **DES sons**. Dr. Green is seeking volunteers to donate one tube of blood at NYU Medical Center, Bellevue Hospital, New York. Contact Dr. Greene at (212) 340-7449 for further details. Results will be given to volunteers if desired.

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	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.

NAME _____

ADDRESS _____

CITY/STATE/ZIP _____

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

Legal Victory in California

Another important legal victory for DES plaintiffs has taken place in California in the suit of Georgiann Kensinger, a DES daughter who had cancer surgery in 1974. On August 22 the state Court of Appeals unanimously agreed that the one-year time for filing suits (statute of limitations) does not begin when a person knows they have been exposed or injured, but when they discover that there has been wrong-doing by the drug companies.

This ruling, in the words of plaintiff attorney Leroy Hersh, "re-opens the window of opportunity granted to DES daughters and sons by the 1980 California Supreme Court *Sindell* decision which allowed DES-exposed individuals to file suit without knowledge of the specific brand of DES to which they were exposed." The *Sindell* decision has influenced courts throughout the nation in broadening plaintiff rights in product liability cases. This latest *Kensinger* decision clarifying the statute of limitations may also have that effect.

Big Crime, Little Punishment

1980—Eli Lilly submits application to the Food and Drug Administration (FDA) to market a new arthritis drug, Oraflex.

1981-82—Lilly learns of at least 28 deaths and many cases of kidney failure, liver failure, or jaundice linked to the drug from its sales overseas; fails to inform the FDA.

April 1982—FDA approves marketing of Oraflex.

April-August 1982—Oraflex associated with at least 26 deaths and over 200 cases of kidney and liver failure in the U.S.

August 1982—Lilly withdraws the drug from the market after Oraflex-related deaths in Britain cause the British government to suspend sales.

June 1983—U.S. begins grand jury investigation in Indianapolis, the home of corporate headquarters of Eli Lilly.

August 1985—Lilly pleads guilty to criminal charges of failing to notify the government of deaths and injuries associated with Oraflex. The Indianapolis grand jury finds no "intent to deceive or defraud the government." Eli Lilly fined $25,000. Lilly former chief medical officer fined $15,000.

Dead: more than 100 people. Ill with non-fatal kidney and liver failure: more than 1,000 people.

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