V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Summer 1988

#37

Ten Years of DES Action Looking Back—And Ahead

By Pat Cody, Co-Founder and International Liaison

A Personal Issue

ost of us can remember exactly when we first learned about DES. I was reading my morning paper one April day in 1971 when I saw the headline "Drug Passes Rare Cancer to Daughters." The minute I read the story I was clutched with fear. There was no doubt this was me; I well remember taking those little pills four times a day for seven months during my pregnancy. My daughter Martha was now 15. I cut the article out and put it away in my bureau drawer. I rationalized that if the cancer was rare, there was little chance she would get it and besides, there probably wouldn't be a doctor who would know about it.

However, I could not put my



Pat Cody

worry away in the bureau drawer. In 1973, when Martha was 17, I told her that she was now a young woman

and that an important part of health care included getting an annual gynecological exam. I found a woman doctor and told her my concern about the DES and that I did not want Martha to know that she had been exposed. She gave Martha what I now know was an ordinary exam, and told me she was fine. It was not until the next year, in May 1974, that I learned from an item in Ms. magazine that DES daughters need a special exam. I found a knowledgeable doctor and realized that now I did have to tell Martha about being DES exposed. It was difficult, but our love carried us through.

After her exam (she's a typical DES daughter and should have this continued on page 3

D E S Action U S A 1 9 7 8 1 9 8 8 10 Y E A R S

How to Receive the Best Medical Care p. 6

DES Action Publications

Medical Updates

by Judith Turiel, Ed.D., Research Liaison

he two largest studies of DESexposed women and men are the DESAD project, coordinated by Dr. Kenneth Noller at the Mayo Clinic, and the University of Chicago DES follow-up program, directed by Dr. Arthur Herbst. Although both studies have suffered severe funding cuts in recent years, they do continue to provide information about DES-related health effects. The DESAD Project issues a yearly update to its study partici-

pants, reporting on the previous year's health questionnaire (this mailed survey, sent to DES daughters and non-exposed women, is the only DESAD research currently funded). Findings from the 1987 questionnaire include the following:

DES daughters do not report higher rates of any specific medical disease.

W Breast problems (cysts, lumps, fibrocystic breasts, cancer) do not continued on page 2

Get Into 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 across 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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DES Action/Netherlands DES-Aktiegroep Maliesingel 46 3581 BM Utrecht The Netherlands MEDICAL UPDATE from page 1... appear to be more frequent among DES daughters.

We no increase is seen in any cancer risk, beyond the well-documented vaginal or cervical clear cell adenocarcinoma.

Preliminary results indicate that DES daughters are more likely to have some type of auto-immune disease. (Auto-immune diseases include a variety of conditions in which an individual's immune system over-reacts, acting against oneself. Examples of auto-immune diseases include: lupus, rheumatoid arthritis, Graves' disease and Hashimoto's thyroiditis.) The "modest increase" in auto-immune conditions will be reported as a "preliminary communication" in Fertility and Sterility (June 1988). Interestingly, DES daughters with vaginal tissue abnormalities (for example, adenosis), considered a sign of higher and/or earlier doses of prenatal DES, had nearly 50% more auto-immune disease than exposed women without such abnormalities, though the difference was not statistically significant. Given these preliminary findings, and the fact that auto-immune conditions often increase or worsen with age, further study is essential (DES Action's 1985 health survey also suggests an increased rate of auto-immune conditions among DES daughters and sons (see VOICE issue #27). In addition, a small study of blood cells from DES daughters, reported in the August 1987 issue of Fertility and Sterility, showed a hyper-reactive immune response, findings consistent with autoimmunity.) In the March 1988 American Journal

of Obstetrics and Gynecology, the University of Chicago program presents their most recent findings on infertility among DES daughters. As in two earlier reports from the Herbst group, DES-exposed women were more likely than non-exposed

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exam every six months) I began to think about all the people who do not read Ms. magazine. I called the state, county and city health departments (I live in Berkeley, California) and wrote to the federal Department of Health in Washington, D.C., to find out what was being done to notify the millions of women who had taken DES. "We're doing a study," they said. "We don't want to alarm women." It was clear to me that the DES issue was being swept under the bureaucratic rug.

How We Began

fter my frustrating phone conversations I got together with a local health educator. We organized a meeting of medics from the local Free Clinic, the Berkeley Women's Health Collective, and others to discuss our concerns about DES. From that meeting came a determination to alert women to the news about DES and the need for daughters to have special exams. We published the first consumer leaflet about DES in mid-1975, 18 months before the U.S. Department of Health issued one. The 500 copies we printed were sent to women's clinics and newspapers all over the United States.

Some copies of that leaflet, "Women Under 30, Read This" reached a San Francisco group, the Coalition for the Medical Rights of Women. Their committees included one on DES, begun by a DES daughter who had similar concerns. The Coalition got in touch with me and I immediately joined them. We revised our original leaflet and distributed 6,000 copies to clinics in San Francisco.

Our next project included contacting the State Health Department's Physicians' Ad Hoc Advisory Committee on DES and convincing them that concerned consumers should be on the committee as well. We worked with this state committee to develop a leaflet on DES and

distribute it to all physicians in California, as well as provide training programs for health professionals in the state. A nurse consultant with the Department also helped us to get a grant from the National Cancer Institute to do a pilot public education program in the San Francisco bay area on DES.

The Early Years

I his was the opportunity we needed, the chance to move from being volunteers doing DES work in our spare time to becoming paid staff preparing professional materials, contacting health providers, doing trainings, and informing the public. My late husband and I had sold our bookstore in Berkeley in 1977, so that we would have time for other interests. This freed me to work on this project, together with Nancy Adess, a health educator and one of the founding members of the DES committee.

In those early years, we were also making connections with other DES groups. My sister on Long Island



called DES Watch. We contacted them, and women from Boston, Connecticut and New Jersey who had also learned about DES mothers and daughters starting to act in their own behalf. Both *The New York Times* and *The Los Angeles Times* published

major stories on us. The Long Island group called a meeting in New York for all of us in May 1977, and that began our linkage.

Late in 1977, Dr. Sidney Wolfe from Ralph Nader's "Public Citizen" group sent a long letter to the Secretary of Health Education and Welfare, Joseph Califano, about a University of Chicago study showing an increase in breast cancer in DES mothers. DES Action member Fran Fishbane travelled to Washington and met with Dr. Wolfe and together they went to Califano's office and did not leave until a special federal DES Task Force was promised. In May 1978, a number of us from DES groups around the country went to Washington to attend a DES Task Force meeting as a reminder that there were real people with real lives affected by the drug. The Ms. Foundation for Women gave us a \$1,800 grant so that we could bring people to this meeting. At the same time, we formally decided to incorporate as a single national organization calling ourselves DES Action, and to help people set up local chapters in other states.

Here in San Francisco, we had just received our National Cancer Institute funding, so we were able to develop materials that could be used all over the country. We produced an updated leaflet, a poster, and a slide show for medical people. The California Department of Health Services, with our collaboration, published a brochure for medical care providers, Guidelines to the Medical Management of DES Daughters. At the same time, our New York group was working on the first state DES legislation. When passed, it set up seven DES health screening centers throughout New York state.

The next year saw the first jury trial of a DES daughter. Joyce Bichler, who developed vaginal cancer at age 18, sued the Eli Lilly drug company and won. As a result,

continued on page 4

TEN YEARS continued from page 3... Joyce and DES Action received much coverage by the press. This attention led to interviews with an Australian journalist, which in turn opened the doors for the formation of our first foreign affiliate, DES Action Australia. Their first newsletter, *DESpatch*, was published in September 1980.

Adding Up the Victories

he year nineteen eighty was memorable in several ways for DES Action. January saw the screening of an episode about DES on "The Lou Grant Show", for which I had the opportunity to be a story consultant. Those of you who saw it may recall that the show was totally sympathetic to the DES exposed. We chose the day the show aired to introduce a DES bill into the California legislature, giving the Health Department money to do education for the public and medical providers on DES. The bill passed that same year.

Our next victory came with a decision by the California Supreme Court ("Sindell") allowing a daughter to sue drug companies for DES-related injuries even if she did not know exactly which manufacturer's product her mother had taken. Legal rights were threatened later that

"The personal is political."

year however when drug company lobbyists tried to pass a law reversing the Sindell decision. Our contacts made while lobbying for the earlier bill now proved very helpful, and we defeated that attempt, as well as a second one in 1982. What skills we were learning! Lobbying, leaflet layout, slide show production, public speaking, fund-raising. . . .

A slogan from the women's

movement that has relevance for me is "the personal is political." That is, what happens in your life very often has social roots or causes beyond your control, and these can be met by working with other people to change such conditions. My second "personal" effect from DES came in 1979 when my daughter Martha had an ectopic (tubal) pregnancy, which required emergency surgery. She lost her right Fallopian tube. As a result, she decided to sue the drug companies. I had a front-row seat for the legal struggles that many of us met with. It became clear that DES lawsuits were complex to handle. To help other attorneys with DESexposed clients, I worked with Martha's attorney and other DES Action members to develop our Information Packet for Lawyers. The packet provides basic information on DES suits for attorneys who may need this kind of assistance.

Action in the 80's

ur grant from the National Cancer Institute ended in 1980, and in 1981 we were awarded a contract from the California State Health Department to carry out public education throughout the entire state. We conducted training programs for health workers throughout California, from the border city of San Ysidro in the south to Eureka nearly a thousand miles to the north, distributing educational brochures for their clients as well. In other states, DES Action members were involved in getting bills passed that would provide funding for public education on DES in their states: Maryland, Florida, Hawaii, Illinois, Maine, Massachusetts, Michigan, New Jersey, Minnesota, Ohio, Oklahoma, Oregon; all passed such legislation in the early 1980s. And once again, a serendipitous visit by a Dutch journalist led to stories about us, this time in Amsterdam, and the DES Aktiegroep of the Netherlands was begun.

In Canada, Harriet Simand of

Montreal was also making the personal political. She later wrote in the *VOICE*:

"I had never heard of DES either, until I was diagnosed as having clearcell adenocarcinoma in 1981. I decided at that point that no other daughter or son would wander around in total ignorance—not if I could help it—so I went to the English Montreal newspaper, The Gazette. On Saturday, Nov. 21, 1981, a front-page story appeared on government irresponsibility and DES. Tuesday, November 24, Health and Welfare Canada gave me a grant to start a DES Action group! The power of the press . . ."

We constantly were learning about the power of the media. Nancy Adess produced our first television public service announcement, featuring Linda Kelsey (who had starred in "The Lou Grant Show"). That 30-second announcement was shown nationally for years and



Linda Kelsey, spokesperson for our first national media campaign.

brought our message to thousands of people. Our own press came into action in 1983 with our best-selling Fertility and Pregnancy Guide and Questions and Answers about DES Exposure.

As DES Action grew, as the publicity we sought spread the word, women and men were eager to start DES Action education and support groups in their communities. By 1982, we had groups in 25 locations; by 1983, there were 32 local DES Action groups. We met with them for training and personal sharing at annual meetings each

continued on page 5

TEN YEARS continued from page 4... October. Nineteen eighty-two also saw the start of the DES Cancer Network (DCN), led by Margaret Lee Braun and Joyce Bichler. It now boasts over 100 members and publishes a newsletter regularly, spreading the word to DES daughters with clear-cell cancer.

In 1984, member Fran Lawler of our Pennsylvania chapter created the Testicular Cancer Network for DES sons. That same year we produced another booklet, *Reproductive Outcomes*, written by board member Joan Emery as a text for medical workers. Joan also helped to write and publish *Working Together*, a handbook on how consumers can collaborate with health providers to achieve better services.

We began 1985 by sending research liaison Judy Turiel to Washington for the second DES Task Force. That year, both the President and the Congress proclaimed DES Awareness Week in April. In June, we were co-sponsors (with the University of California) of a national research conference on DES. In July, Nancy Adess, board member Kim Klein, and I went to the United Nations Decade for Women conference in Nairobi, Kenya. There we met with our Canadian and Dutch affiliates and together we gave out leaflets, had scores of interviews with foreign journalists, and put on a workshop about DES. We learned that DES is still being given to pregnant women in many parts of the world, including most of Latin America and much of Africa. We have an ally in the European-based group, Health Action International (HAI), which has sent material about DES to health centers around the world.

If we ever need reminding of why our work is important, we received it in 1986, when after six steady years of work, we got the law changed in New York so that DES daughters who had had cancer were no longer shut out of court. Susan

"Perseverance does pay off. If you believe in something enough and don't give up on the cause, you can help to create change."

Helmrich of the DES Cancer Network spoke for all of us when she wrote in the *VOICE*:

"Perseverance does pay off. If you believe in something enough and don't give up on the cause, you can help to create change."

That is the spirit that has sustained our local chapters, that leads to new groups like the ones just begun in Texas, Oklahoma and Washington state, all performing the invaluable work of being there for people who learn they are exposed and need our resources. Local chapters answer the mail and phone calls, appear on their local media, do workshops, hold public meetings, and sometimes get involved in legislation.

It was in that spirit that we sent Judy Turiel to a scholarly conference on "Hormonal Carcinogenesis" a year ago, where she did a poster

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Poster panel from 1987 research conference.

presentation about DES Action and our research interests. Likewise, I was able to attend the 5th International Women's Health Conference in Costa Rica and do workshops (in Spanish and English) on DES. That was in May; in July, while on a vacation in France, I was interviewed by the women's magazine Marie Claire and learned about a DES mother with four DES-exposed children (all of whom have had related health problems) who wanted to start a group in France. Our Dutch group got in touch with her, she attended our Annual Meeting last October, and now we have our fourth international affiliate, Action DES France.

The Present and Beyond

ere we are in 1988. With the help of two major grants we've been able to get our own computer, produce a new television message and send it

for the first time to major stations in all 50 states as well as to over 1,600 radio stations. We also are working on a booklet on breast cancer risks, to clarify the confusion about this major health problem. And we continue to keep a wat



ch on legislation both nationally and in the states, to see that our legal rights are not taken away in the guise of "tort reform." There are always challenges and opportunities—"when you have a lemon, make lemonade." Together, we have made a difference and we will keep on making a difference.

How to Receive the Best Medical Care

by Andrea Goldstein, National Program Committee Member and Coordinator, DES Action Massachusetts

The following is excerpted from a workshop presented by Ms. Goldstein at the fall 1987 DES Action annual meeting.

PART I

The Search for a DES-Knowledgeable Physician

- Ask friends, current physicians, and local hospitals (teaching if possible) for their recommendations. Also, consult with your local DES Action group or the national office in San Francisco. Check these physicians with the Directory of Medical Specialties, available in the reference room of most local libraries.
- Check your health insurance. Some prepaid plans restrict your choices to those doctors at their satellite centers, or to those doctors who belong to the plan. In some instances, this can be circumvented if the plan has no appropriate specialist for patients' specific needs. The health plan will then pay accordingly.

PART II

Getting Started

- Call the physician's office and inform the staff that you wish to interview the physician. Ask to be booked for extra time if you feel you will need it, and if so offer to pay extra. Ask the office about the doctor's training and hospital affiliations (the directory mentioned above will provide much of this info as well).
- Talk openly about your needs, both medical and emotional; get to know the doctor by questioning her/his methods of treatment.

- Ask about laboratory/pathology affiliations. Check these out if you have any concerns.
- Toos this person have experience in your specific area of need, or can you be referred if necessary? (Examples: Oncology, high risk obstetrics, infertility, endocrinology, microsurgery/laser surgery.)
- * Learn how the office functions. How are routine calls handled? Does the doctor have a call-back hour? How are emergencies handled? Who provides alternate coverage when the doctor is unavailable? (Check that person out as well).

PART III

Personal Housekeeping

- * Keep copies of all your medical records. File them away in a loose-leaf notebook, categorized by physician and date.
- Ask that a copy of the latest entries to your chart be sent along to you at the office's convenience.

PART IV

The Appointment

- * Try to prepare questions in advance. (Keeping them on index cards is a good way to be organized.) Take notes. Index cards are good for this too.
- If the doctor does not have copies of all of your records, you may wish to bring them along yourself, at least for the first visit.
- We Bring a spouse or a friend. If you tend to get nervous, she/he can function as an extra set of "ears," and can take notes for later review.
- W Bring copies of articles that relate to your problem or the mode

of treatment you wish to discuss. If the doctor makes recommendations, ask her/him to provide articles and/ or other sources of information for you to help with your decisionmaking.

W Make sure you have time to go over the visit after the exam—in the doctor's office and fully clothed.

SUMMARY

- We Be organized and methodical in your search for a new physician.
 - Plan out your visit.
- Take as much time as you need. Don't be rushed!

Remember, you are ultimately responsible for the quality of health care you receive. You have more control than you think. Be an informed consumer of health care services, and an active participant in your relationships with your health care professionals.



Support Received

Ms. Foundation for Women

DES Action USA
would like to extend its
thanks to the
Ms. Foundation for
Women for a recent
\$3000 grant to support
our work.

DES Action Publications Order Form

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DES Exposure: Questions and Answers for Mothers, Daughters and Sons	\$2.00	drugs that can affect the fetus. It gives practical and safe alternative remedies to such common		
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Women and the Crisis in Sex Horomones, by Barbara Seaman and Gideon Seaman, M.D., revised edition, 1982. Special sections on DES, oral contraceptives, and menopausal estrogen.	\$3.00	DES Exposure: Q & A Fertility and Pregnancy Reproductive Outcomes Women and the Crisis in Sex Hormones	\$2.00 \$ \$6.00 \$ \$3.00 \$ \$3.00 \$	
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Preventing Preterm Birth: A Parent's Guide.		name		
Topics covered include: the basics of preterm labor, prenatal care, self-monitoring for pretern labor, diagnosis of preterm labor, bedrest at home, cerclage, tocolytic medications, what		address		
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MEDICAL UPDATE from page 2... women to experience primary infertility (33% vs. 14% had never been pregnant after at least one year of trying). Of all women with primary infertility, a smaller proportion of DES daughters eventually conceived (58% vs. 64%, as of February 1986), and took longer to do so. Among women who did eventually become pregnant, 73% of DES daughters and 56% of the nonexposed women conceived independently of fertility treatment. As in many previous studies, DES daughters were more likely to experience a pregnancy loss than non-exposed women.

Structural abnormalities of the cervix and vagina (for example, cervical ridges, adenosis) at a DES daughter's first pelvic exam were more common among those with primary infertility. These signs may help identify individuals who are

more likely to have fertility problems; however, the abnormalities often disappear over time and, therefore, may not be seen by a doctor who examines a DES daughter at a later time. A normal or abnormal hysterosalpingogram (Xray of uterus and tubes) did not predict which infertile DES daughters would eventually conceive. Although specific factors contributing to infertility are difficult to identify, the authors highlight tubal defects that may reflect past or present pelvic inflammatory disease (PID). They suggest aggressive antibiotic therapy if PID is suspected (including treatment of a woman's sexual partner, to decrease the recurrence of sexually transmitted diseases).

These updates demonstrate the importance of continued research on DES effects as exposed women and men grow older. DES Action contin-

ues to encourage further studies our involvement with research issues, for example, contributed to consideration of immune system effects by the DESAD Project, as we hope it will by the Herbst group in the near future.

Unfortunately, the U.S. government seems unwilling to continue adequate funding for DES research. Without the needed money, the flow of new information about DES exposure, which is already slowing to a trickle, may soon come to a halt. Because Congress controls the federal research budget, we encourage you to write to your U.S. Senator or Representative to encourage him or her to support such research funding. You can also join our DES Legislative Action List by contacting our national office in San Francisco.



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