DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

Vol. 5, No. 1

Summer, 1983

Meeting with NCI

DES Action Underscores Need for Continued Research

In the early 1970s there was concern about how many DES daughters would develop vaginal and cervical cancer. Now the risk of pregnancy problems in daughters has been verified. As the DES generation moves along, there may be other health concerns.

The DES story is far from over: most daughters and sons are only now in their twenties and thirties. We—and many scientific researchers—are convinced that the research necessary to understand DES effects must continue.

On April 26, 1983, DES Action President Nancy Adess and Board Member Amy Fine met with officials of the National Cancer Institute to discuss needed ongoing research into these and other questions concerning effects of DES exposure.

First we looked at the major research to date. The National Cancer Institute funded a seven-year study—the DESAD study—to look at the incidence of the vaginal and cervical clear cell cancer in daughters. Conducted at five major medical centers throughout the U.S., the DESAD project provided free screening exams to 3,339 DES daughters and their matched controls (women the same age but not exposed to DES). Along the way, the study came upon other problems: pregnancy problems in the daughters, and questions about increased abnormal cell growth on the cervix (dysplasia). Some of the research centers also questioned daughters about other problems which might—or might not—be related to their DES exposure.

Many questions were answered by this study. We now know that DES daughters' risk for clear cell cancer is between 1-in-1,000 and 1-in-10,000, depending on age (the greatest risk is between 19 and 22). We also know that DES daughters are definitely at greater risk for problems during their pregnancies than non-exposed women. These problems include higher rates of tubal pregnancy, second trimester miscarriage, and premature labor and delivery.

But many questions have not been answered, and the money to study further cancer risks has run out. In May, the National Cancer Institute decided not to renew the funding for the DESAD study in its current form, asserting that the major cancer risk is now known. DES Action urged the Institute at least to enable the study to keep contact with the women it has been following for so many years, so that we could learn of future problems if any appear. But it may be another year before funding for even such minimal follow-up is available.

Without careful assessment of potential risks, DES people could be affected by delay in needed care. For example, it took many cases of cancer for medical practitioners to institute special exams on a routine basis for all DES daughters to watch for the early signs of cancer developing. In another example, a closer look at the potential of DES exposure to affect a woman's ability to carry a pregnancy to term might have prevented many needless miscarriages or deliveries of premature infants. Studies done now can give us peace of mind. If there are any risks for older DES daughters and sons, the sooner we know about them, the better we can protect our health. Research needs to examine, for example, whether DES daughters will have a greater risk of breast cancer than other women, and whether higher rates of dysplasia, if they exist, will be associated with a higher risk for cervical

You can add your voice to ours. Write your Congressmember asking that she/he urge the National Institutes of Health to fund necessary DES-related research. Since Congress funds the National Institutes of Health, a Congressmember's letter carries weight. Address your requests to: Your Representative, House Office Building, Washington. D.C. 20515; and Your Senators, Senate Office Building, Washington, D.C. 20510. If possible, send us a copy of your letter.

-N.A.

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Is There a DES Action in Your Community?

If your community is not listed below, contact DES Action's New York Head-quarters for help in starting a local DES Action group. DES Action groups provide education to the public and to health professionals about DES, and help the thousands who were exposed

DES Action/Arizona Suite #221 P.O. Box 16200 Mesa, AZ 85201 DES Action/California:

> 1638-B Haight St. San Francisco, CA 94117

P.O. Box 481

San Rafael, CA 94902

P.O. Box 1303

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1172 Morena Blvd.

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c/o YMCA, 1122 17th St. Sacramento, CA 95814

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626 12th Ave.

Two Harbors, MN 55616

c/o YWCA, 1130 Nicollet Ave.

Minneapolis, MN 55403

DES Action/Missouri

4712 Milentz

St. Louis, MO 63116

DES Action/Montana

c/o Tester, Rt. 1, P.O. Box 2950

Arlee, MT 59821

If your community is not listed below, to DES find out about their exposure and the care they need.

If your community *is* listed below, contact your local group to see how you can help. Your active volunteer participation helps DES Action stay active!

DES Action/New Jersey

P.O. Box 22

Fort Lee, NJ 07024

DES Action/New Mexico

P.O. Box 40270

Albuquerque, NM 87196

DES Action/New York

Long Island Jewish Hospital

New Hyde Park, NY 11040

DES Action/New York City

P.O. Box 331 Brooklyn, NY 11229-0331

DES Action/Ohio:

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P.O. Box 14755

Cleveland, OH 44114

P.O. Box 2691

Akron, OH 44301

DES Action/Oregon

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P.O. Box 12092 Portland, OR 97212

DES Action/Pennsylvania

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Spokane, WA 99203

P.O. Box 15869

Seattle, WA 98115

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c/o Snowdon, P.O. Box 233

Montreal, Quebec, Canada, H3X 374

DES Action/The Netherlands

DES-Aktiegroep

Maliesingel 46, 3581 BM Utrecht

The Netherlands

DES Action/Australia

P.O. Box 282

Camberwell, Victoria 3124

Book Review

GETTING PREGNANT IN THE 1980s by Robert H. Glass, M.D. & Ronald J. Ericsson, Ph.D.

by Joan Emery

Getting Pregnant in the 1980s reviews current issues in human reproduction and reproductive technology, including infertility, pregnancy after thirty-five, in vitro fertilization, drugs and pregnancy, and sex preselection. The book is very readable for those at all familiar with reproductive biology, and includes a brief illustrated appendix on human reproduction for readers who want to "brush up."

The authors convey a balanced view of the potential and limits of reproductive technologies. In discussing infertility, for example, they remind the reader that aspects of infertility lack a scientific understanding, and that cures attributed to medical interventions may in fact be spontaneous. After these initial cautions, they offer cogent explanations of known causes of infertility and corresponding tests. Throughout this chapter, there are sensitive references to the emotional aspects of infertility, accompanied by referrals to support groups (RESOLVE) and to other methods for coping with emotional problems that may arise.

The discussion of drugs and pregnancy is brief, presenting the latest available research conclusions about safety of the most common broad drug classifications (antibiotics, hormones, sedatives, etc.). The research conclusions are prefaced with the advice: "Avoidance of all but prescribed medications and drugs, and keeping those to an absolute minimum, is a good rule during pregnancy, or for that matter at any time of life."

DES is mentioned as part of the discussions on infertility and miscarriage. The authors point out the association between DES exposure and pregnancy problems. There is no mention of the number of people exposed to DES, and emphasis is on reassurance that "the majority of DES-exposed women have unimpaired fertility." The only other

Continued on page 8

The **DES Action Voice** is published quarterly by DES Action National, Inc.

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President: Nancy Adess. Vice President: Dolores Wallgren. Treasurer: Pat Cody. Secretary: Libby

Editorial Staff: Nancy Adess, Joyce Bichler, Joanne Derbort, Dolores Wallgren.

Partnership for Health

by Project Staff: Kris Brown, Joan Emery, Judith Turiel

A two-year project designed to demonstrate how consumers and providers can work together to improve care and provide support and information for DES exposed men and women has been started by the DES Action group in San Francisco.

Since its founding in 1975, DES Action-San Francisco (a committee of the Coalition for the Medical Rights of Women) has concentrated on public outreach to the estimated 1 in 20 people who are DES daughters, sons, or mothers in order to inform them of their special health care needs. Funded by the San Francisco Foundation, the lames Irvine Foundation, the Henry J. Kaiser Family Foundation, and the Fred Gellert Foundation for a total of \$63,000 over two years, the new project expands DES Action's work by focusing on quality and comprehensiveness of medical care for DES exposed people.

The project is designed as a cooperative approach between a consumer group and medical providers in various settings. Its goal is to help DES exposed people participate more effectively as consumers of health care by improving access to information and support, and by encouraging productive doctorpatient communication.

As in many areas of medical practice, DES-related health care is characterized by considerable professional disagreement and by continually changing information. DES Action staff hear frequently of DES daughters' difficulties in getting clear, comprehensive information from medical providers about reproductive tract changes associated with DES, and about risks and benefits of medical procedures commonly used with DES daughters. Project funding will allow staff to develop ways to strengthen the position of the consumer—for example, by organizing DES discussion groups, and creating written materials that will assist DES exposed people in obtaining the information they need and in expressing their concerns during medical exams.

Project activities are divided into three main areas: 1) establishing relationships with medical providers, including those with greatest experience in DES-related care; 2) providing support and information to DES exposed men and women; and 3) developing a system for keeping up on, understanding, and encouraging further DESrelated research.

Toward establishing relationships with health care providers, we have talked with doctors and nurses who are involved in cancer screening and fertility and pregnancy care for DES daughters. We interviewed practitioners from a variety of settings, including a large university medical center (University of California, San Francisco), small clinics, and private practices. We introduced ourselves, the project, and DES Action and asked for their perspective on how we might work together. As a result of

have started a study group that meets every three weeks to discuss current DES research articles. For example, a recent study group meeting focused on articles concerning the diagnosis of ectopic (tubal) pregnancy. (DES daughters have a higher than normal incidence of this potentially life-threatening condition.) Several questions arose from our discussion which we will pose to medical advisors in order to obtain a better picture of the safest diagnostic methods presently available. Diagnosis of ectopic pregnancy is only one area of rapidly changing knowledge and technology. We will be developing a system to improve access to accurate, current health

The project's goal is to help DES exposed people participate more effectively as consumers of health care . . .

these interviews, we have begun developing a communications network with local medical providers. Several are now reviewing our written materials, and have offered to respond to specific medical questions.

Support and information services have also started. We run an ongoing support/ discussion group for women who are at risk for pregnancy problems. In addition to DES daughters, this includes women who are carrying twins, have diabetes or hypertension, have had a previous premature delivery, etc. We have also held discussion groups for DES daughters only-where we shared information about basic gyn care, as well as about fertility and pregnancy. Project staff are working with DES Action National on a "Guide to Fertility and Pregnancy Care for DES Exposed Men and Women." It will be available in the fall, and will provide information and guidelines for working with doctors in considering diagnostic procedures and medical treatments in case of fertility or pregnancy problems.

In the third area—developing a system for keeping up with, understanding and encouraging further research—we

information, which DES exposed women and men can discuss with their doctors.

Project staff is encouraged by the progress so far. Medical professionals are not usually accustomed to working with active, well-informed consumers. However, we have now identified some very interested doctors, nurses and midwives. We look forward to developing new ways of combining our resources as a consumer organization with their medical expertise toward the mutual goal of high quality, comprehensive health care for DES exposed women and men.

Attention Artists

DES Action is holding a contest to design the 1984 DES Awareness Week campaign poster. For information on how to enter, write: DES Action National, 1638B Haight Street, San Francisco, CA 94117.

Medical Abstracts

"Seminoma and Epididymal Cysts in a Young Man with Known DES Exposure in Utero." Conley, G.R.; Sant, G.R.; Ucci, A.A.; and Mitcheson, H.D. Journal of the American Medical Association, March 11, 1983, pp. 1325-6.

Before this article, no case of testicular cancer had been reported in a man exposed to DES in utero. The authors describe a 20-year-old man with a malignant seminoma (testicular tumor), and epididymal cysts, whose mother had taken DES throughout her pregnancy, at doses up to 105 mg, per day. The pregnancy and delivery were uncomplicated: bilateral hernias were repaired at age two. The young man's cancer was treated successfully with surgery and radiation therapy. Since the cysts were lined by columnar epithelium, DES was almost certainly the cause. (Cysts not related to DES exposure are rarely lined by this type of tissue.) The authors guessed that no cases had been reported before for a number of reasons: either testicular cancer patients are not asked or do not know about their DES exposure; or DES-induced seminomas would not have been expected prior to this decade because these cancers often occur in men in their 30s; or a relationship may not exist between the DES exposure and the cancer.

After the article was written, the authors added a postscript. They had found another DES-caused seminoma, in a 27-year-old man. This was treated by surgery and chemotherapy. The patient had five DES exposed siblings: one sister with vaginal adenosis, another with vaginal adenocarcinoma, and a brother with severe oligospermia (low sperm count).

Editor's note: Dr. Sant has informed DES Action that since publication of this article, he has heard of other cases of testicular cancer occurring in DES exposed males. He states that a connection between DES exposure and the cancer is *very* preliminary and much more work is required before any definitive statements concerning the direct relationship of DES and the development of testicular cancer can be made.

Dr. Sant is setting up a study on DES males at Tufts University School of Medicine and the New England Medical Center in Boston. He would like any doctors or other interested parties, including patients, to notify him of any abnormalities and/or cancers developing in

DES exposed males. Write: Grannum R. Sant, M.D., Tufts University School of Medicine, New England Medical Center, Department of Urology, 171 Harrison Avenue, Boston, MA 02111.

"Transition of Benign Vaginal Adenosis to Clear Cell Carcinoma." Ghosh, T.K., and Cera, P.J. *Obstetrics and Gynecology* 61(1), January 1983, pp. 126–30.

The patient described in this case study was followed for six years at the Geisinger Medical Center DES Clinic in Pennsylvania. She was first diagnosed as having vaginal adenosis at age 21; her menstrual and reproductive history (one uncomplicated pregnancy, one miscarriage) were not unusual. Colposcopic examinations were performed regularly and consistently showed only adenosis until age 27, when biopsy of a granular area in the vagina revealed clear cell adenocarcinoma. Radical hysterectomy, pelvic lymph node removal and formation of a neovagina were performed and at the writing of the article, she was free of disease.

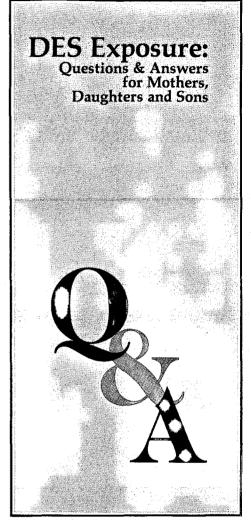
The authors suspect transition from the benign adenosis to malignancy; however, detailed tissue study failed to show clear transition. Thus, the development of cancer from adenosis has still not been established beyond a doubt.

Editor's note: As with previously reported articles by Dr. Veridiano and Dr. Anderson, this article is a reminder of the need for frequent, careful follow-up of DES daughters to look for cancer.



The Carpenteria (California) Quilters are quilting an antique quilt top to benefit DES Action National. Contact your local chapter or the National office for information on how to win this quilt.

New Booklet Available



DES Action National has just published a new, comprehensive booklet about DES exposure. "DES Exposure: Questions and Answers for DES Mothers, Daughters and Sons" is a 16-page booklet containing the latest information about DES exposure. The new booklet provides in one place a thorough review of current medical information about the effects of DES exposure on mothers, daughters, and sons, as well as special sections on how to get your medical records and a detailed description of the DES examination for daughters. "DES Exposure" also contains a listing of the most common names under which DES was sold, and quotations from medical sources concerning the use of oral contraceptives by DES daughters.

To order "DES Exposure," see order form, next page.

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Previous issues of the DES Action Voice contain articles by experts about the medical and legal ramifications of DES exposure and reports about the personal experiences of those exposed by DES mothers, daughters, and sons. Please see reverse for a listing of contents of all issues.

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Reference Text for Physicians: Developmental
Effects of DES in Pregnancy by Arthur Herbst,
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New developments in sex hormone abuse Pelvic inflammatory disease and DES daughters Vaginal infections: caring for yourself DES Action Canada

Creating DES Awareness: A National Campaign

by Linda Usdin, National Media Coordinator

The first national DES AWARENESS WEEK Campaign was held April 18–23, 1983. The goal of this campaign was to help people find about about DES, and whether they were exposed to this synthetic hormone. Thirty-four communities around the United States participated in the campaign. In each of these communities local DES Action volunteers contacted local radio, TV, and newspapers, as well as other organizations, to get the DES Action message out: Find out if you were exposed. Ask Your Mother.

It is difficult to summarize a campaign that has so many components and so many results. All of the local group reports are not yet completed, so actual numbers are not available. It seems, however, that the real measure of the campaign can be seen in other terms: how many people were reached, what networks were created with other organizations and governmental representatives, and how the campaign built internal strength for DES Action as an organization.

The most difficult aspect to measure is how many people were reached, because we do not know how many people went directly to their doctors or health centers after hearing our messages. We do know that almost every local DES Action group has noted a sharp increase in mail and/or telephone

requests. In addition, the national office in New York reports that they are receiving about 150 requests a day from around the country! Many people may not write in immediately, but may be motivated to write in the coming months.

During DES AWARENESS WEEK, DES Action groups contacted Planned Parenthoods and other reproductive support groups, health departments, schools, colleges, women's groups and other organizations in their communities. The DES Action groups provided information and materials and offered presentations. The campaign not only gave DES Action an opportunity to hook up with these groups, but also greatly expanded the numbers of people we can reach. In several communities, the League of Women Voters, Planned Parenthood, the Womens Clubs, and other local women's organizations did special mailings that included our short information brochure.

During DES AWARENESS WEEK, people were also reached through public meetings. Twenty local groups sponsored public meetings during DES AWARENESS WEEK. Each of these meetings provided information and the chance to join DES Action's work.

The campaign also provided a focus for many people who had been peripheral volunteers. Numerous volunteers helped deliver posters and pamphlets, make presentations on radio and television, and organize public meetings. As a result, many volunteers had the opportunity to develop new skills.

For DES Action as a whole, this campaign was a great boost in forming new groups. In the months of planning the campaign, nine new contacts called the national office in San Francisco for assistance in holding campaigns in their communities. This has since led to the formation of new groups in many of these communities.

Local DES Action groups concentrated their activities on getting our message out through the media, since that has proven to be the most effective way of reaching the largest number of people. Thirteen DES Action groups gained media interest with proclamations from mayors, governors or state legislators declaring April 18–23 as DES AWARENESS WEEK. Press conferences were also an effective way of getting the media to cover the issue.

Certainly one of the most reliable and effective ways of getting media coverage is to continue to build a bigger and increasingly vocal national organization. The more often DES Action members are present and vocal, the more publicity we will get—and the more people we will be able to reach. There is no doubt that this first national media campaign reached many thousands.

CONGRESSIONAL RECORD

DES AWARENESS WEEK

HON. TED WEISS

OF NEW YORK

IN THE HOUSE OF REPRESENTATIVES

Thursday, April 21, 1983

• Mr. WEISS. Mr. Speaker, I rise to support DES Awareness Week, April 18-23, 1983. DES ACTION, a national organization dedicated to educating the American public about the uses and consequences of diethylstilbostrol (DES), has designated this week as a time to locate and educate the many women and men who have no knowledge of their exposure to this potentially dangerous drug.

Between 1940 and 1971, doctors pre-

Between 1940 and 1971, doctors prescribed this synthetic estrogen to millions of pregnant American women to prevent miscarriage. Early in 1971, the

medical community witnessed a dramatic rise in the incidence of a rare vaginal and cervical cancer in young women whose mothers had received DES-related drugs during pregnancy. Subsequent medical research revealed a strong connection between DES and cancer of the reproductive organs. In benign abnormalities addition. throughout the reproductive tract have been documented in DES daughters. Because the DES daughter and son cohort is relatively young, the increased risk on their life cycles cannot yet be fully evaluated.

As a result, careful gynecological and urological monitoring may be necessary for these young women and men. Indeed, DES daughters are advised to have regular and sometimes special gynecological observation and exams. Their current physicians need to be aware of their patients' exposure

to DES so they can update their medical histories and insure proper medical attention.

Yet, there are still many among the estimated 4 to 6 million Americans affected by DES who do not know of their exposure. In some cases, DES mothers did not provide informed consent for their DES treatment, further complicating the task of identifying and educating their children. Important medical attention and treatment may thus be forfeited.

DES Awareness Week is a much needed opportunity to focus national attention on the problems of the millions of DES-exposed Americans. It is vital that DES mothers, daughters, and sons be informed of their exposure. I am proud to play a role in this educational process, thereby helping to increase the opportunity for them to receive proper medical care.

Letters to the Editor

Dear DES Action National Workers:

I couldn't let our daughter's birth go by without telling you. I am a DES daughter, victim of dysplasia, cone biopsy, miscarriage, ruptured ectopic pregnancy, second ectopic pregnancy (tube saved), incompetent cervix, cerclage and Delalutin shots, plus a difficult Caesarian section (breech birth position). Even when I almost gave up, something pushed me on. I had lots of support from my husband, family and friends. Now we are thrilled to have our daughter, Sara Barbara, with us to make our marriage into a family.

Thanks for your answers to my questions, the advertisements and articles on TV and in the printed press, and the newsletter. Keep up the good work.

Beth Shelley

Dear Editor:

I am interested in hearing from any DES daughter who has experienced repeated miscarriages in her first trimester, and who has achieved a successful pregnancy after undergoing treatment. What treatment was given, especially if a small T-shaped uterus was attributed as the cause of miscarriage? I am especially interested in hearing from anyone who has undergone surgical reconstruction for a T-shaped uterus.

Please write to: Mary Boles c/o The Voice

Continued from page 2

notable reference to DES appears in the chapter on miscarriage, in which DES is cited as the prime example of unfortunate results arising from physicians' desire to "do something" to preserve a pregnancy.

The chapter on sex preselection corrects some popular recent theories on the effect of timing of intercourse on offspring gender. The work of Ericsson and others shows this approach does not increase chances of bearing either a

boy or girl. The only sex preselection method which is at all effective to date is one which increases the chance of having a male from the usual 50% to 75%. This method, developed by the author, Ronald Ericsson, involves artificial insemination with sperm that have undergone a filtration process to separate out the Y (male) chromosome.

Getting Pregnant in the 1980s makes smooth transitions among reproductive facts, theories and ethics. The authors readily acknowledge unanswerable questions in each of these realms. The final chapter presents the reader with a set of common questions that are answerable, and the question and answer format results in easy, interesting reading. The reader is encouraged to seek answers to additional questions in this field by asking physicians and by consulting medical journals such as Fertility and Sterility. This advice is consistent with the tone of the entire book-respectful of the lay person's capacity to research, understand, evaluate, and make difficult choices about reproduction and reproductive technologies.

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