V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Winter 1997

medical report

#71

Health Concerns for DES Sons

"The Effects on Men of Prenatal Exposure to Diethylstilbestrol," by Cynthia J. Laitman, Morten Jonler, and Edward M. Messing: Chapter 14 of Infertility in the Male, Third Edition, Edited by Larry I. Lipschultz M.D. and Stuart S. Howards M.D., Mosby Publishers, 1997.

he authors begin their report with noting that, despite the fact that 1 to 3 million men in the United States are DES sons, little research has been done on them, compared with the many studies on DES daughters. They write that studies of the sons have centered on urogenital abnormalities, fertility, and cancer of the urogenital tract, and go on to state:

"More recently, interest has been renewed in DES sons as a model for a much broader and more pervasive concern—the effects of environmental chemicals on male fertility and urogenital abnormalities and pathologic

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abnormalities, especially as these chemicals may act transplacentally. Chemicals with estrogenic activity include almost all pesticides, herbicides, and insecticides in current widespread agricultureal use, as well as industrial chemicals such as dioxin."

The authors describe the landmark Dieckmann study on DES exposure, undertaken to learn if in fact DES did prevent miscarriage, and published in 1953, just a year or so after the children were born to women who had taken part in this study. Without realizing it, the researchers who set up this study at the University of Chicago were providing a "guinea pig" group that would be studied in the future for effects from the DES exposure:

"This study showed that DES did not reduce the number of miscarriages or premature or postmature births, nor did it decrease the incidence of late-pregnanxy complications such as toxemia or eclampsia. The children whose mothers participated in that study continue to be of medical interest as de facto subjects of the only prospective, double-masked, controlled human study in the long-term effects of DES."

Twenty five years later, William Gill M.D., a urologist at the University of Chicago, did an evaluation of 308 DES sons and 307 controls from this group. They found a significantly higher incidence of epididymal cysts on the testes, smaller testes, undescended testes, and small penises among the DES sons. Fifteen years later, researcher Allen Wilcox M.D. interviewed sons from this study to gain information about fertility.

"Results indicated no impairment of fertiity by any measure in the DES exposed men....
However, the DES-exposed group did report urogenital malformations three times more often than the non-exposed control group. Those men exposed to DES before the 11th week of gestation had twice the prevalence of malformations as

continued on page 3

DES Action Affiliates

Each group was created and nurtured by volunteers. Write them if you want information on their activities or can volunteer.

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DES Action/Netherlands DES-Aktiegroep Wilhelminapark 25 3581 NE Utrecht ES (diethylstilbestrol) is a synthetic form of the female hormone estrogen. From 1938 to 1971, several million pregnant women in the U.S. were prescribed DES, especially if they had a history of previous miscarriage or slight bleeding or had diabetes. DES was given in pills, injections and suppositories and sold by over 200 drug companies under their own brand names.

DES exposure can lead to health problems:

- DES mothers have an increased risk for breast cancer
- ☼ DES daughters have a 1 in 1,000 risk for a rare vaginal/ cervical cancer, clear-cell adenocarcinoma. This is the reason all daughters need regular gyn exams. They also are at risk for reproductive difficulties: infertility, ectopic pregnancy, miscarriage and premature delivery, and should always receive high-risk pregnancy care.
- DES sons have an increased risk for undescended testicles, cysts on the epididymus, and possibly for infertility.

DES Action, the major consumer group working on this issue since 1974, has special publications, physician referral lists, attorney referral lists, this quarterly newsletter, and a hot-line:

1-800-DES-9288.

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V O I C E

medical reports

Breast Cancer Risks

"Breast cancer and hormonal contraceptives: collaborative reanalysis of individual data on 53,297 women with breast cancer and 100,239 women without breast cancer from 54 epidemiological studies," by Collaborative Group on Hormonal Factors in Breast Cancer, *The Lancet* Volume 347, 22 June 1996.

his lengthy article with its charts, graphs and tables is the largest study yet on the question of a relation between breast cancer and the use of oral contraception. The data comes from 25 countries from all five continents, first world and third world. Other hormone exposure, such as inutero exposure to DES, was not questioned. The conclusion:

"The relation observed between breast cancer risk and hormone exposure is unusual, and it is not possible to infer from these data whether it is due to an earlier diagnosis of breast cancer in ever-users, the biological effects of hormonal contraceptives, or a combination of reasons.

"Interpretation. Women who are currently using combined oral contraceptives or have used them in the past 10 years are at a slightly increased risk of having breast cancer diagnosed, although the additional cancers diagnosed tend to be localised to the breast. There is no evidence of an increase in the risk of having breast cancer diagnosed 10 or more years after cessation of use, and the cancers diagnosed then are less advanced clinically

than the cancers diagnosed in never-users."

"Induced Abortion and the Risk of Breast Cancer," Melbye, M. et al, *N.E.Journal of Medicine*, 9 Jan 1997.

ontroversy over whether an induced abortion (as distinct from a miscarriage which some physicians call a "spontaneous abortion") in-

SONS *from page* 1... those exposed to the drug later."

Later in this chapter, the authors raise the question of cancer risk for DES sons. First, in referring to testicular cancer, they note that research shows that congenital abnormalities such as undescended testes predispose to both cancer and infertility. Thus,

"prudence dictates that men prenatally exposed to DES, with their disproportionately high prevalence of urogenital anomalies, be considered an at-risk population for malignancies until proved otherwise."

The authors then turn their attention to prostate cancer, "despite the absence of clinical data on the effects of prenatal DES exposure on the human prostate." They point out that experimental studies show changes in human prostate tissue exposed during its developmental state to DES:

"Human fetal prostatic rudiments grown for one month in male mice developed squamous metaplasia of the prostatic utricle and urethra in all mice treated with DES, but did not develop in the untreated controls... creases the risk of developing breast cancer later in life has apparently been ended with a new study. Danish researchers, according to New York Times writer Jane Brody, studied abortion histories from official registries of all Danish women born between 1935 through 1978. Over these 43 years, they found that among the 1,529,512 women covered, there was no more risk for breast cancer among those who had had an abortion than there was for women who had never had an abortion.

Although no human studies of a possible link between prenatal exposure and prostate cancer have been conducted, it must be remembered that the DESexposed population has not yet reached the high-risk cancer age range but will during the first decade of the 21st century. Based on existing evidence, DES sons may be at increased risk of cancer of the prostatic utricle. Because utricular cancer does not cause an elevation in prostate-specific antigen (PSA), it is possible that the standard means of screening for prostatic cancer may not be effective in this population. For men with utricular cancer, it is possible that hematuria (blood in the urine) may be a prime indicator rather than PSA or digitalrectal examination."

The chapter concludes with stating that "it appears likely that there is a dose-response relationship between DES and developmental anomalies in men exposed prenatally to DES" and emphasizing the need for further studies to definitely determine the risks of DES sons for cancer of the testes and of the prostate.

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Notes from Nora

everal Internet-friendly members responded to our appeal for a DES news group, and we now have one coordinated by volunteer Sally Glover. DES-exposed individuals have been "chatting" via the newsgroup for some time now, offering information and support to one another. Sally invites everyone to check out the group and join the ongoing conversation. The name of the group is alt.support.des and it is available on aol and other servers. If you can't find it, contact your server's newsgroup administrator and request that it be added to the list of newsgroups.

T T T

Symposium 1997: Come to Boston!

We have continued with plans for our 1997 Symposium, which will focus on reproductive technologies and coping with menopause. There will be a general session with several speakers and several workshop sessions.

We are fortunate to have secured the participation of the following four speakers for our general session:

Judith Turiel, Ed.D., health educator and editor of *Preventing Preterm Birth*, A *Parent's Guide*, and author of upcoming book on today's reproductive technologies.

Ms. Turiel is an expert in the field of fertility treatments and has just completed a book on reproductive technologies and

"In addition to our four keynote speakers, the symposium will include workshops that will allow for more discussion and for DES mothers, daughters, and sons to exchange information and personal experiences."

their consequences (to be published by University of California press). She is a DES daughter who has herself experienced high-risk pregnancy and preterm labor.

Dianne Dumanowski, co-author, Our Stolen Future, reporter, The Boston Globe.

Our Stolen Future is a prominent recent book that has been called The Silent Spring of this generation. It describes the threat posed to the reproduction of humans and wildlife by a world increasingly burdened by estrogenic chemicals, pesticides, etc. DES serves as the best example of the disastrous results of estrogenic chemical intake on humans.

Janine O'Leary Cobb, editor, *A Friend Indeed*, menopause newsletter.

Ms. Cobb is an expert on menopausal treatments and has written extensively on alternatives to drug therapy. **Burton Krumholz, M.D.,** Director DES Screening Center, Long Island Jewish Hospital.

Dr. Krumholz is known to many DES daughters for his many years of practice through the DES Screening Center. He is an expert on the effects of DES experienced by DES daughters.

In addition to our four keynote speakers, the symposium will include workshops that will allow for more discussion and for DES mothers, daughters, and sons to exchange information and personal experiences.

The symposium is open to any member and is a great opportunity to meet other DES-exposed people and to have your questions answered. There will be a fee for attending to cover the costs of food and facilities.

The Symposium will be held Saturday, October 18 at the Ramada Hotel in Andover, MA (near Boston). Please contact me if you are interested in attending, and I will put you on the mailing list and make sure that you get registration materials.

T 7 7

We've added two new affiliates to our list. Kathy McKay and Judith Pressmar have started a group in Montana and Julianna Lerner leads our new affiliate in New Mexico. We welcome and thank these volunteers, and invite any members in those states to contact the affiliates for more information (addresses listed on p. 2).

Follow Up DES European Study

In January 1997 DES Action the Netherlands started a new project titled "The use of diethylstilbestrol in Europe." It will be a follow-up of the DES European Study which was completed in 1991." In this project we will collect data on the use of DES in European countries and will evaluate to what extent information is available for the medical profession and the general public.

The study has been divided into two parts. For one part we

will select countries where we believe there is a reason to look again into the use of DES. For these countries we think it important to make an update of the information collected in 1990/91.

In the other part, in three socalled spearhead countries, a more intensive survey than in the other countries will be done. For this we selected the UK, Spain and Poland. Despite many signs that DES has been used in these countries there is still no exact knowledge and/or recognition about the extent of it. Neither is information available for the general public and the medical profession.

The study will be done by means of a written questionnaire. The whole project will be carried out under the supervision of an international review committee.

We have asked the European Commission Programme "Europe Against Cancer" for a grant. The report will be published in October 1997."

Older Volunteers Needed

from Office of Cancer Communications

he National Cancer Institute (NCI) is looking for 75,000 more men and women ages 55 to 74 to evaluate screening tests for some of the most common cancers (prostate, lung, colorectal and ovarian cancers). Doctors are already aware that medical tests can detect tumors of the prostate, lung, colon or ovaries before a person shows any symptoms, and NCI is seeking to determine whether the rigorous use of screening tests can reduce the number of deaths. For those involved with DES Action, with a heightened awareness of cancer, and particular concerns about reproductive cancers, determining the validity of cancer screening tests is especially important.

Collectively, the cancers addressed by the Prostate, Lung, Colorectal and Ovarian Cancer Screening Trial (PLCO Trial) are responsible for nearly half of new diagnoses and half of all cancer deaths tallied in the United States

today. PLCO Trial sites are located in 10 cities: Denver, CO; Washington, D.C.; Honolulu, HI; Detroit, MI; Minneapolis, MN; St. Louis, MO; Brooklyn, NY; Pittsburgh, PA; Salt Lake City, UT; and Marshfield, WI.

The trial participants are randomly selected to receive the tests under study or to continue their usual medical care. Both groups will answer a questionnaire about their health each year. Half of the participants in the study receive tests and half do not. In order to determine whether the cancer screening tests have any benefit, researchers need to compare the numbers of cancers diagnosed and the number of cancer deaths in the intervention group with the cancers diagnosed and the cancer deaths in the control group.

In November, NCI reported that the cancer death rate in the U.S. fell between 1991 and 1995, the first sustained decline since national record-keeping was instituted in the '30s. Although the cause of the decline is unclear, as is the sharp rise in deaths preceding the decline, hopefully the '90s will be remembered as the decade when the tide against cancer was turned. Maintaining this new momentum, however, requires a recommitment to research and provides DES Action supporters with an opportunity to serve.

Interested women and men should call the NCI's Cancer Information service at 1-800-4-CANCER to make contact with the PLCO Trial. Additional information can also be found on the World Wide Web at http://www.dcpc.nci.nih.gov/PLCO.



V O I C E

letters to the editor

Dear Editor:

I read with amazement the Letter to the Editor about eye problems (Fall 1996). I, too, have an eye problem which seems to me (a layperson) to be very different. I experience episodes of temporary monocular (one eye) blindness for about three to five minutes at various intervals ranging from as often as once a week to as seldom as once a month. Various medications have been ineffective in stopping the episodes. I have been tracking the dates and times of the episodes over the course of three years in order to find a pattern (time of day, stress level, unusual foods, etc.) Attempting to link it to my hormonal levels or menstrual cycles have been difficult and unsuccessful. I was born with no uterus or fallopian tubes (after DES exposure), so while my doctor has found evidence through blood work of ovulation, I have no menstrual cycle and therefore no simple way to track

hormonal levels (I've tried temperature taking with no success).

Is anyone else out there like me? I'm told my case is completely unique, and I was assured that DES only affects the developing fetus at the time of fertility organ development (of course, I was also told that 25 years ago when I didn't get my period). What's up?

Reader New York City

Dear Editor:

I am writing to you to request that you might put me in touch with other DES daughters with similar problems as myself that I will list below. I would be very interested in comparing stories about facing certain issues with someone directly.

First of all, I am 35 years old and did successfully settle a lawsuit (out of court) several years back with a DES drug manufacturer. After enduring years of infertility treatments, my husband and I have two beautiful adopted children and couldn't be happier!

However, in addition to the gynecological "anomalies" that DES has left me with, my two specific ongoing problems that are likely DES-related are "corneal erosion" and "vulva sclerosis" (thinning and splitting of tissue).

I remember reading an article in your newsletter (ed.—issues 68 and 69) about someone with corneal erosion...and I was curious how they deal with it. Having worn contacts for years until November 1995 when this problem flared up, I hate the thought of having to wear glasses forever. My opthamologist has no suggestions for me other than wait and see.

As far as the other condition, I have been told by various doctors that it is very rare to find in young women my age except in DES daughters. After seeking a diagnosis and remedy from many doctors, I was able to find a treatment from one specialist that helps when the problem gets very bad. While there is apparently no cure, perhaps I could share my findings with someone else with the problem to save them the years of frustration and discomfort I experienced.

DES Daughter Virginia

Editor's note: You can send replies to us and we will forward them to the writers of these letters.

DES Action Tribute Program

We'd like to offer a great idea for that person who has

everything: the DES Action Tribute Program. Our Tribute
Program is a way for you to make your contribution in
someone's honor or memory. Holiday gifts, birthdays,
anniversaries or memorial remembrances—all are
appropriate occasions for a Tribute Gift.
When you send your tribute gift to DES Action, simply
enclose a note indicating in whose honor and for what
occasion the gift is given. Make sure to include the honoree's
name and address as well as your own. We send an
acknowledgment letter to you and the honoree. The
amount of the gift is not mentioned.

Early Detection by Mammography

e are reading more and more about breast cancer these days, in good part because of work by consumer groups to see that more research is done. Part of this research is concerned with the age to start annual mammography. The risks for breast cancer, like that for many cancers, is agerelated, with the highest risks for breast cancer found among women in their 80's. Studies in the past on when to start mammography have not concentrated on younger women, or, the studies have had serious flaws.

When to start has been clouded with controversy. Many important organizations: American Cancer Society, American Medical Association, American College of Obstetricians and Gynecologists, American College of Radiology, American Women's Medical Association, National Medical Association, American Society of Therapeutic Radiology, and American College of Pathology, recommend regular screen-

ing beginning at age 40. On the other side, against screening women under the age of 50, have been the National Cancer Institute, American Academy of Family Practice, American College of Physicians, and United States Preventive Services Task Force. A conference is scheduled for January that could resolve these differences.

For the present, health writer Jane Brody of the New York Times reports that the trend in recent studies shows a clear decline in breast cancer deaths if women in their 40's have regular mammograms. She quotes Dr. Stephen A. Feig of the Breast Imaging Center in Philadelphia as stating that if women in their 40's had annual mammograms it would result in a 35-50% reduction in breast cancer deaths. A second physician, Dr. W.P. Evans from the Susan G. Komen Breast Center at Baylor College of Medicine, reported that half the cancers in women under 50 found at their facility were discovered at the in

situ (local) stage which is nearly 100% curable. In a response to Ms Brody's article, Dr. Daniel Kopans, Director of Breast Imaging at Massachusetts General Hospital, wrote "Mammographic screening can reduce the death rate from breast cancer by at least 25% for screening beginning by the age of 40."

We want to emphasize that the studies referred to covered women in the U.S. in general, not DES daughters. Apparently the researchers did not ask women about DES or other hormone exposure. As we noted in our last issue, we do not know if DES exposure in utero is associated with breast cancer. But, since early detection is critical to survival for any patient, we believe that it is important for our readers to be aware of the significance of starting mammography by age 40.





Join DES Action!



Yes - I want to get the answers about DES. Enclosed is my membership.

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☐ Benefactor: \$1000 and above ☐ S		porter: \$100	☐ Other:		•
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Conference on Hormones

group of British doctors has set up DASH—Doctors Against Abuse from Steroid Sex Hormones (the pill, HRT, exogenous progesterone and estrogen). They are calling a conference, in conjunction with the Society for Allergy, Environmental and Nutritional Medicine, to be held in London on 4 June at the Royal Society of Medicine. The areas covered include "How Hormones Work," "Thrombosis and Osteoporosis," "Hormones and Cancer," and "Looking Ahead."

In a letter to prospective members, DASH declares its mission as

- 1. To provide realistic information on the side effects of exogenous hormones
- 2. To protect the health of women and their families
- 3. To provide an open forum for exchange of information.

The physicians who are organizing DASH are concerned about recent reports that HRT can cause primary thrombo-embolism; that use of the pill increases risks for breast cancer, and whether HRT is

effective in preventing osteoporosis. In a recent letter, Elizabeth H. Price, M.D. wrote:

"Shouldn't women be warned of the dangers? Contraceptive pill warnings in the 70s were followed by marked falls in breast cancer registrations for a decade among the specific age groups involved. This was against the prevailing trends. Overall,...data shows large increases for England and Wales. For women now aged 55-64, the incidence of breast cancer has more than doubled, increasing by 137% between 1962 and 1991. These women were aged 25-34 in the 60s when they became the first generation to be exposed to the contraceptive pill.

"Doctors must now review whether it is a defensible or ethical practice knowingly to give healthy women contraceptive or menopausal hormones when increases in breast, ovarian cancer and thrombosis have been demonstrated in reputable studies. Even any long-term benefit of fracture prevention is being questioned."

DES Action USA

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