DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

Vol. 3, No. 2

Fall 1981

DES LEGISLATION: Effective and Far-Reaching

Since 1978, when the first bill to aid DES-exposed people was introduced in New York State, DES-exposed people and state legislatures alike have seen the need for laws to help state health departments locate and provide medical screening for DES-exposed people.

Legislation is probably the most effective way to reach millions of people and a necessary tool for many reasons. Many DES-exposed people still do not know of their exposure. Many who do know they're exposed still do not know they need special examinations. The high cost to patients of the screening exams means that many will forego these necessary tests rather than face continuous medical bills. Lastly, many physicians are not trained or equipped to provide the special examinations DES daughters need, so their patients go without proper care.

Legislation can be a valuable aid in all of these circumstances if it contains the following provisions:

- Mass public education about DES and the need to discover if one is exposed.
- Identification of medical centers that can serve as screening centers on a sliding fee scale basis.
- Training of health professionals at these centers so they provide complete and competent care.
- Outlawing insurance company discrimination against those exposed to DES.

If all these conditions are met, then legislation will be truly beneficial to DES-exposed individuals.

While one-disease bills may not be the best way of administering state health programs, most state health departments cannot mount effective DES campaigns without some special funding. In fact, many states have passed bills to aid victims of other diseases – cerebral palsy, cystic fibrosis, and cardiac defects among them. Legislators, in order to aid the victims of DES exposure similarly, must understand three things:

- that DES is a severe, widespread, hidden (and therefore potentially treacherous) health risk.
- that a statewide program can be effective in the early detection of malignancies.
- that the political reality is that little will be done in most states without a special bill.

In states where legislatures do understand the DES issue and the needs of DES-exposed people, bills have been introduced by sympathetic legislators and passed,



Governor Harry Hughes of Maryland signs DES bill while Delegate Joan Pitkin, sponsor of the bill (directly behind Governor Hughes), Lillian Tompkins and Dolores Wallgren of DES Action look on (standing to Delegate Pitkin's left).

often without difficulty.

On Page 7 of this issue is a listing of the bills that have been introduced in a number of states since 1979, the provisions of each bill, and the current status of each. For more information on any particular bill, write to the DES ACTION office of the state in question.

Thanks to Sally Goldfarb, whose excellent paper on DES legislation, prepared for Yale Legislative Services, provided background information for this article.

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DES ACTION Groups in Action...

GREAT LAKES, MINNESOTA purchased a DES Tel-Med for a hospital in Duluth. A 5-minute tape on DES is now available when the hospital receives information requests concerning DES. The Duluth Community Health Center has opened a DES

screening center.

HAWAII is joining forces with family planning groups to gain exposure through inclusion in their in-service training and workshop sessions. By working with Hawaii Planned Parenthood the group hopes to reach the DES-exposed on Hawaii's neighbor

MINNEAPOLIS, MINNESOTA will teach a class for the Saint Louis Park School District Continuing Education Program this fall. A DES presentation with two community physicians which will emphasize fertility and pregnancy concerns. Legislators who sponsored the DES bill will also be honored at that time. Joyce Bichler has been promoting her book DES Daughter extensively in the area. This has prompted many calls and new contacts.

NEW JERSEY continues to provide counseling and information at Bergen Pines DES Clinic. Peer support groups are forming this fall. They are also attempting to establish liaisons in key areas throughout the state to organize

'subgroups'.

MICHIGAN has renewed contact with agencies throughout the state and has sent them samples of the new son and daughter pamphlets. The group continues to participate in health fairs. Following Joyce Bichler's apperance on the "Today Show", DES Action Michigan was featured on "Closer Look", Lansing's NBC affiliate.

MASSACHUSETTS has scheduled a meeting for October in Framingham. A letter is being prepared to inform health clinics and nursing schools about the DES slide show. Their physician survey has enabled the group to offer referrals in many Massachusetts communities.

CALIFORNIA: The San Bernardino group has worked with county health department and some physicians to get a DES Daughter's clinic started.

The Los Angeles group has held a number of well attended meetings.

The San Diego group is doing inservice training sessions for clinics in their area.

San Francisco is planning an Educational in November with the goal of attracting 50-100 people. Two physicians, DES Action staff and DES daughters, including a nurse practitioner, will be present to provide information and answer questions.

The group has also had a first meeting with medical staff from the University of California at San Francisco's DES Clinic where they refer many DES daughters. They hope to establish communication with the goal of improving medical care there. For starters, they will be giving patients their handout, which announces who they are, where they are located, their telephone number, and that they offer DES daughter support and information-sharing groups to which DES Clinic patients are invited. They will be getting a tour of the facilities and an orientation to the procedures and then will meet again with the medical staff to establish ways to work together.

New Groups Organizing

Local DES Action groups are forming in the following areas. They will hold informative meetings and rap groups. If you are interested, contact:

Chicago: Maryann Rosenblum, 211 Krotiak, Park Forest, Illinois 60466

Houston: Joyce Tautenhahn, 2118 Cobble Creek, Houston, Texas 77073

Albuquerque: Barbara Jellow, 306 Mesa SE, Albuquerque, NM 87106

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

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DES Action/Florida 9586 Portside Dr. Seminole, FL 33542

DES Action/Hawaii 1521 So. King St. Honolulu, HI 96826

DES Action/Louisiana 3631 Rue Nadine New Orleans, LA 70114

DES Action/Massachusetts P.O. Box 126 Stoughton, MA 02072

DES Action/Michigan P.O. Box 66, East Lansing, MI 48823

DES Action/Great Lakes 626 12th Ave., Two Harbors, MN 55616

DES Action/Minnesota YWCA, 1130 Nicollet Ave. Minneapolis, MN 55403

DES Action/New Jersey P.O. Box 323, Westwood, NJ 07675

DES Action/Nevada P.O. Box 5748, Reno, NV 89513

DES Action/New York Long Island Jewish Hospital New Hyde Park, NY 11040

DES Action/Ohio 551 N. Drexel Ave. Columbus, OH 43209

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Implementing the Legislation: NEW YORK DES PROGRAM

by Donna Glebatis-Feck, Director

The New York State DES program was the first state-legislated program established in the United States to deal with the adverse health effects associated with in utero exposure to diethylstilbestrol. In August 1978, the New York legislature passed and Governor Carey signed the DES bill creating the DES program within the New York State Department of Health. In addition to dealing with presently known adverse health effects, the NY DES Program is committeed to carrying out long-term follow-up and research into other health problems associated with DES exposure that may appear in DES mothers, daughters and sons in the future. To achieve these ends, the DES program was designed to include three major components: 1) education; 2) screening; and 3) registration of DES mothers, daughters and sons.

EDUCATION

A few months after the DES program was created, a telephone survey of 1,000 randomly selected women throughout New York was conducted to determine how aware the public is about DES. It was found that only 40% of the women surveyed had ever heard of DES and of those, the majority were uninformed regarding the facts about DES exposure. Therefore, a DES public education campaign was launched in May of 1979 to raise the awareness level of the public regarding DES. This multimedia campaign used news releases, public service announcements on radio and TV, brochures, posters, counter cards, billboards, transit cards and magazine ads. Numerous health and professional organizations around the state were contacted to serve as local distributors of the educational material. The theme "DES: The Wonder Drug Women Should Wonder About" was carried throughout the campaign. During the first eighteen months of the campaign 700,000 brochures, 2,000 posters and 5,500 counter cards were distributed throughout the state. Space for 10,000 transit cards and 100 billboards was donated.

After 1½ years of intensive effort, a

second follow-up telephone survey was conducted. The results showed that awareness had risen from 40% to 70%. With DES awareness levels increased in New York, the DES program is now directing its public education efforts towards local community outreach activities around the state.

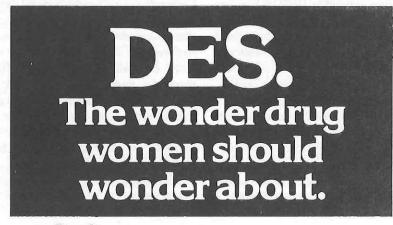
SCREENING

To assure availability of quality medical care for DES-exposed individuals a statewide network of statefunded DES screening centers has been established. Only centers approved by a committee of experts on DES are included in the program. Each center provides DES examinations for DES daughters and refers DES sons to a urologist experienced in examining males for health problems associated with DES exposure. All centers have trained staff available to provide individual patient education and counseling and to discuss the results of the examination. Some centers also offer group discussion and education sessions. A schedule of periodic follow-up examinations is determined by the center physician and is carried out either at the center or by the woman's private physician, depending on the patient's preference. Anyone exposed to DES or suspected of being exposed can contact any of the centers directly to talk with a center staff person and make an appointment. For persons not covered by health insurance, the fee for the DES daughter examination is determined by a sliding scale based on ability to pay.

REGISTRY

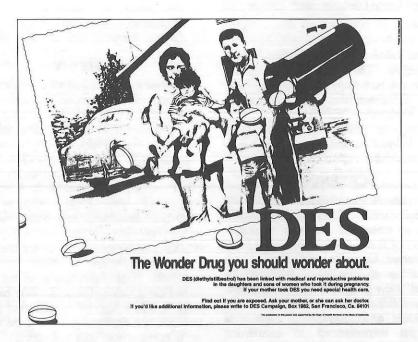
A voluntary, confidential registry of DES-exposed individuals has also been established. The purpose of the registry is two-fold: 1) to keep registrants informed of new developments in research regarding DES exposure and 2) to carry out long-term follow-up and research on other health problems that may be associated with DES exposure in mothers, daughters and sons. Registrants are sent comprehensive health history questionnaires which are used as the basis of long-term follow-up and research. These questionnaires are updated on a yearly basis. Similiar health information is also being obtained from persons not exposed to DES to be used as a comparison (control) group. This mechanism will allow early identification of other health problems associated with exposure should they occur. Known or suspected DES-exposed individuals are encouraged to join the state DES Registry. Only through the cooperation of a large number of DES-exposed individuals can adequate follow-up and research be carried out. Persons interested in joining the New York State Registry can obtain a registration form by writing to the NYS DES Program, Room 565-Tower Building, New York State Department of Health, Nelson Rockefeller Plaza, Albany, New York 12237.

Pictured below, campaign slogan as seen in both literature and on posters throughout New York.



Implementing the Legislation: CALIFORNIA DES PROGRAM

by Pat Cody



Imagine:

- •Watching television some night and at a "message" break there is Linda Kelsey talking about DES and why you should learn if you are exposed.
- Listening to your radio and hearing a similar announcement.
- Going to your pharmacy and seeing a poster on "DES – The Wonder Drug You Should Wonder About."
- Finding the same poster at the checkstand of your local supermarket or in your weekly shopping paper.
- •Picking up a new leaflet at a health clinic with that motif.

All these things are going to happen starting in October in California, thanks to legislation created in 1980 by Senator Diane Watson. SB1392 gives the State Department of Health Services (SDHS) money for a public and professional education campaign and the designation (but not financing) of screening centers. It also states that health insurors cannot exclude, reduce, or otherwise limit coverage for DES-related conditions.

DES Action/San Francisco has a contract with the state to carry out the public education part of this bill. Linda Usdin and I are staff for the project. We spent the summer working on all the materials

described above and setting up networks of health care professionals and DES Action members who will be of vital importance in making the campaign a success. We've been putting on workshops for health providers all over the state, centering on our slide/tape show, so that when people come to them with questions they will have accurate and up-to-date information. We found that county health departments are especially responsive; some of them are reinforcing our efforts by making their own plans for public education on DES.

Professional education on DES is being conducted by the SDHS in a series of one-day seminars for physicians and nurses in six different regions of California during September and October. The seminars include training in the clinical procedures for DES examinations, and will add significantly to the roster of health care providers who can meet the needs of the DES-exposed. California, with its 24 million population the largest state in the union, has accordingly the largest number of DES-exposed: an estimated 600,000 to 1.2 million (mothers, daughters, and sons).

We want to reach all of them, beginning with "DES Awareness" week in mid-October.

DES-Action, Nevada

The American Association of University Women has funded DES-Action, Nevada through an AAUW Research and Projects Grant. This state-wide public information program was initiated by the Reno branch of AAUW in 1980 and was joined enthusiastically by the remaining branches in the state in 1981.

The grant monies will provide literature and publicity to be distributed throughout the state, and establish a "warm line" answering service to receive calls dealing with general information and specific problems related to DES exposure. DES-Action's warm-line staffers will attend training seminars hosted by AAUW in Reno and Las Vegas.

Nevada's relatively small population is spread out among hundreds of miles. In rural areas of the state, which often have no physicians, public health nurses are the only available source of medical advice and treatment. Spread throughout Nevada, the 10 AAUW branches will disseminate DES information to their areas, thus reaching both outlying regions and residents of the more densely populated cities of Reno and Las Vegas. This will be accomplished within the one-year time frame of the grant's guidelines.



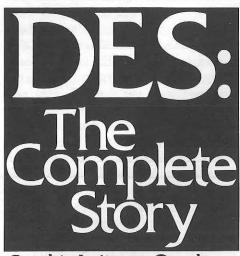
Erratum:

In the Summer 1981 issue of the VOICE, we inadvertently omitted the author's by-line for the article "The Redbook Article: The Author's Reactions". That article was written by Judith Turiel, author of the DES article which appeared in *Redbook* magazine, February, 1981.

MORE BOOKS

DES: The Complete Story

by Cynthia Orenburg



Cynthia Laitman Orenberg Introduction by Howard Ulfelder, M.D., Joe V. Meigs Professor of Gynecology, Harvard Medical School

DES: The Complete Story, by Cynthia Orenburg is being published for the general public in November by St. Martin's Press. As the title indicates, it is all about DES. The book documents the development of the drug, the drug's effects on daughters, sons, and mothers, and gives practical suggestions for dealing with the effects of the drug. The author discusses the legal impact of DES lawsuits, the government's handling of DES as an approved drug, what drugs preganant women are still being given and more. Cynthia wrote the book from two perspectives: as a DES mother and as a professional medical writer. DES: The Complete Story provides a thorough examination of the entire DES episode and is written for the reader without a science background. An extensive bibliography is also included for readers who want to delve into the subject further.



Author Cynthia Orenberg with her family. From left to right, Kate (age 12), Cynthia, Rachel (age 8), and Max.



DES Action recommends the following book to your physician as a definitive background and reference text about DES. The book, clothbound, is available for \$29 from:

Thieme-Stratton, Inc. 381 Park Avenue South New York, N.Y. 10016

The following is a list of the contents and contributors:

Introduction and Background, Arthur Herbst, M.D., and Howard Bern, Ph.D. Embryology of the Genital Tract in Humans and Rodents, John-Gunnar Forsberg, M.D., and Terje Kalland, M.D.

Developmental Effects of Diethylstilbestrol (DES) In Pregnancy

Arthur L. Herbst, M.D. and Howard A. Bern, Ph.D.

Pathology of the Female Genital Tract after Prenatal Exposure to Diethylstilbestrol, Robert Scully, M.D., and William Welch, M.D.

Cytologic Diagnosis of Diethylstilbestrol-Related Genital Tract Changes and Evaluation of Squamous Cell Neoplasia, Yao Fu, M.D., James Reagan, M.D., and Ralph Richart, M.D.

The Epidemiology of Vaginal and Cervical Clear Cell Adenocarcinoma, Arthur Herbst, M.D.

Clinical Correlations and Management of Vaginal and Cervical Clear Cell Adenocarcinoma, Arthur Herbst, M.D., and Diane Anderson, B.A.

Genital Findings: Colposcopic Evaluation, and Current Management of the Diethylstilbestrol-Exposed Female, Kenneth Noller, M.D., Duane Townsend, M.D., and Raymond Kaufman, M.D.

Male Genital Tract Changes in Humans Following Intrauterine Exposure to Diethylstilbestrol, William Gill, M.D., Gebhard Schumacher, M.D., Marian Hubby, Ph.D., and Richard Blough, M.S. Effects on the Mother Following
Exposure to Diethylstilbestrol in
Pregnancy, Marian Hubby, Ph.D.,
William Haenszel, Dr. P.H., and Arthur
Herbst, M.D.

Neonatal Mouse Models and Their Relation to Disease in the Human Female, Howard Bern, Ph.D., and Frank Talamantes, Ph.D.

Rodent Models for Perinatal Exposure to Diethylstilbestrol and Their Relation to Human Disease in the Male, John McLachlan, Ph.D.

Diethylstilbestrol Metabolism in Humans and Experimental Animals, Manfred Metzler, D.Sc.

Immunological Consequences of Early Exposure of Experimental Rodents to Diethylstilbestrol and Steroid Hormones, Phyllis Blair, Ph.D.

Stromal-Parenchymal Interactions in Normal and Abnormal Development of the Genital Tract, Gerald Cunha, Ph.D., and Hirohiko Fujii, Ph.D.

Present Problems and Future Concerns, Howard Bern, Ph.D., and Arthur Herbst, M.D.

DES AND SCIENCE

Dear Doctor

Dear Doctor.

In the June 8, 1981 issue of Medical World News there is a report about eleven DES daughters who had laparoscopy for infertility diagnosis. The researcher, Dr. Alan DeCherney, reported that all of them had "shriveled" Fallopian tubes with little or no fimbrial tissue, and that 10 of the 11 had T-shaped uterus. The article suggests that this shriveled tube may be why DES daughters have a higher rate of ectopic pregnancy.

I know from my reading that ectopic pregnancies can be very serious because of the risk of internal bleeding. Because DES daughters have ectopic pregnancies more often, do you think that DES daughters who want to get pregnant should first have a uterine/tubal X-ray (hysterosalpingogram) to find out if their tubes are blocked and/or if they have a T-shaped uterus?

Answered by Dr. A.F. Haney, Director Division of Reproductive Endocrinology, Duke University.

The information now available regarding what effect DES exposure may have on fallopian tubes is scant at best, but efforts such as Dr. DeCherney's are beginning at least to show that DES exposure may alter the anatomy of the fallopian tube.

There is good data suggesting an increased rate of ectopic pregnancies in DES daughters, with approximately 3-5% of all pregnancies occurring in the fallopian tube. As this is a potentially lifethreatening hazard, it is important that any DES daughter who feels she is pregnant confirm the pregnancy as early as possible. Once a pregnancy is clearly present, a simple ultrasound exam of the pelvis can document its intrauterine (in the womb) location.

If there is a positive pregnancy test but the ultrasound exam does not locate a pregnancy in the uterus, then ectopic pregnancy is strongly suggested and this combination alerts both the patient and her doctor to this possibility.

Unfortunately, hysterosalpingography is a rather poor assessor of tubal anatomy other than obstruction in the tubes, which is not necessarily related to DES exposure. Even if a DES daughter has a normal hysterosalpingogram, there is no documentation yet that she does not have the same increased risk of ectopic pregnancy as the DES daughter whose x-ray is abnormal.

On this basis, I think it is safest to assume that anyone exposed to DES prenatally has an increased risk of an ectopic pregnancy. Therefore, the patient and her doctor should document the intrauterine location of the pregnancy as early as possible by ultrasound, which is safe and economical, and should minimize the hazard to the patient even if an ectopic pregnancy is present.

Medical Abstracts

"Reproductive problems in the DESexposed female". David L. Rosenfeld and Richard A. Bronson. Obstetrics and Gynecology, vol. 5 (no. 4): p. 453, April 1980.

The authors report the reproductive difficulties of 25 DES daughters, all of whom sought medical attention because they could not become pregnant or because they could not carry a pregnancy to term. Therefore, this article does not shed any light on the overall incidence of reproductive difficulties in DES daughters.

What it does do is confirm the observations of others who have reported on the kinds of problems DES daughters experience. These problems include primary infertility, or inability to conceive (12 out of 25 women in the study); secondary infertility or, inability to carry to term (13 out of 25 women); ectopic pregnancy; abnormal cervical mucus; T-shaped uterus; and incompetent cervix.

The authors conclude that apart from

by Cynthia Orenberg Madison, Wisconsin

prescribing fertility drugs (clomiphene citrate) to induce ovulation or performing a cerclage for incompetent cervix, there are no real solutions to the problems experienced by their patients.

"Randomised trial of high doses of stilboestrol and ethisterone in pregnancy; a long-term follow-up of mothers." Valerie Beral, and Linda Colwell, British Medical Journal, vol. 281: p. 1098, October 25, 1980.

In England in 1950 (at the height of DES use in the United States), the London School of Hygiene and Tropical Medicine supervised a multicenter study to determine the effectiveness of sex hormones in preventing miscarriage in severely diabetic women (diabetic women have a well-established high risk of miscarriage).

In all, 156 women were enrolled in this double-blind, randomized study. Eighty of them received a combination of ethisterone (an artificial progestrone compound) and DES; 76 women received placebos.

This article reports on the results of a follow-up study of these women 30 years later, revealing that four of the hormone-treated women developed breast cancer compared to none in the control group. This supports the results of a University of Chicago study of close to 700 DES mothers and a similar number of controls in which more DEStreated mothers developed breast cancer than did control mothers. Unlike the Chicago study, the British study showed that hormone-treated women also had more benign uterine tumors and more benign fibrocystic breast disease than other women, two conditions not noted in the Chicago study.

It should be noted that the British study employed even more massive doses of DES than most American women received, i.e. 20 grams or more as compared to 10 or 11 grams. A second difference was that the British women also received an artificial progesterone compound simultaneously with the DES.

CURRENT LEGISLATION ON DES, Continued from Page 1.

| STATE | PROVISIONS OF BILL | | | | | STATUS AMT OF FUNDIN | | |
|------------------------------|--|-----------------------|-------------------|---------------------------------------|----------------|---|--------------------------|--|
| | | Screening Centers* | Prof. Training | Voluntary Registry | Insur- ance | | The Distor | |
| California SB 1392 | X | X | Х | | X | Passed 1980 | \$172,000 | |
| Florida HB 184 | -, | | 9 - <u>L</u> | li (=3 <u>≥</u> | X | Passed | | |
| Hawaii | Hope to introduce a bill next session. Resolution passed 1981 | | | | 8 | | T set l set l | |
| Illinois HB 127 | X** | X | - | X | X | Passed 1979 Mandate for implementation of all bur measure rescinded, 1980 | ion of all but insurance | |
| Maine | X** | X | === | X | X | Passed 1979 | none | |
| Maryland H 994 H 995 | _ X | _ X | _ X | | X - | Passed 1980 | | |
| Massachusetts S 651 | Х | X | Х | 151 - YI. 41 | Х | Being considered for the third time. | \$90,000 asked | |
| Michigan HB 5061 | | X*** | X | - | - | In Committee | | |
| Minnesota 62A 154 HF 1512 | - X | _ X | = | _ X | X _ | Passed 1981 To be heard, Fall 1981 | none | |
| New Jersey S1179 | X | X | Х | Х | - | Passed 1979, vetoed by Governor. Passed 1981, Awaits Gov.'s signature. | | |
| New York | Х | X | Х | X | X | Passed 1978 | \$350,000 | |
| Ohio | Bill will be introduced next session. | | | | | | | |
| Oklahoma | Х | Х | X | X | _ | Pending | All of the second | |
| Oregon | | Resolu | tion passed | d, 1980. | | | | |
| Federal | | the 1980 ses | | 546 were intr will be reintr 1. | | | | |

Linda Kelsey, National Honorary Chairperson for DES Action, has filmed two Public Service Announcements on behalf of DES Action. Urging everyone to find out if they might be exposed to DES, Kelsey says, "DES – The Wonder Drug You should wonder about – NOW!" and refers listeners to DES Action for further information.

These television spots will be aired, free of charge, by television stations all over the country beginning later this fall.

Members will be receiving a special appeal to help pay for buying copies of the film to go to stations around the country. If you would like to enable DES Action to produce more copies of the film to go to television stations, or if you can help see that your favorite television station airs this spot, get in touch with Nancy Adess at the West Coast address: 1638B Haight Street, San Francisco, CA 94117.

KELSEY STARS IN DES ACTION PUBLIC SERVICE ANNOUNCEMENT

Enclosed is my tax-deductible gift.



SUPPORT DES ACTION!

☐ Subscriber: \$15-25
 ☐ Receives subscription to the DES ACTION VOICE quarterly newsletter.
 ☐ Friend: \$50-250
 ☐ Receives the VOICE plus Joyce Bichler's book, DES DAUGHTER.
 ☐ Supporter: over \$250
 ☐ Receives all of the above plus annual reports on the organization's progress.

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address ______city/state/zip _____

Letters To The Editor

Dear Editor,

I am a thirty one year old man whose mother took DES when she was pregnant with me. I feel it is important to share my story. Last October, I began experiencing discomfort in my left testicle. When I began noticing a change in its shape, I went to the doctor. He thought it was an infection and referred me to a urologist who decided to do exploratory surgery. In November the teste was removed and a small mass was discovered inside. It was diagnosed as malignant and I was referred to another urologist and a cancer specialist. In December, I was admitted to the University of Rochester Strong Memorial Hospital to undergo an operation to remove lumph nodes. These were examined under microscope and declared free of any stray cancer cells. I was released and pronounced "cured" with one small exception. Every month I have to go back to the Cancer Center and have extensive blood tests and chest x-rays to be sure the cancer has not come back. The doctors say this cancer can recur in other parts of the lymph gland system or in the lungs. It is not an easy thing for a young man in the prime of life to live with. Also, my wife and I thank God that we have three healthy sons because as a result of my second operation, I am unable to have any more children.

Although the doctors say there is no proof my cancer was caused by DES, I feel there is no proof that it wasn't.

This story is unfinished and no one can tell how it will end, but it could have been much worse. That is why I am hopeful that you will be able to alert other males who have been exposed to the drug to have annual physical exams and to note any changes in their genitals. The doctor told me that men should perform a regular monthly testicular self-examination on themselves much as women do for breast cancer. I had never heard of this before and feel it is an important point that should be stressed.

J.W., New York

DES Action's pamphlet, "You may be

A DES Son," explains how to do testicular self-examinations. For a copy, send a stamped self-addressed envelope to your local DES Action group (see Page 2 for a listing of DES Action groups across the country) or to DES Action National, Long Island Jewish Hospital, New Hyde Park, New York 11040.

Dear Editor:

Thanks for telling us about Joyce Bichler's book. It's an inspriration to read how she surmounted her truama and fought back, acting for all of us. I got so angry reading about her trial, and then I decided to use the energy of the anger to tell as many people as I can about DES to find out if they're exposed, and even if they're not, to learn from our experience.

It's so important to know something about drugs you're prescribed, about what the research was and what the side effects are. And, most important, you are the one to decide if you want to take any medication.

Robbie Young, San Francisco

DES ACTION, National

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