THE DES ACTION

V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Fall 1996

#70

Breast Cancer Among DES Daughters?

by Deborah Wingard, Ph.D., Associate Professor Community and Preventive Medicine, University of California-San Diego Medical School.

ello again! I am a DES daughter who shared my experience with breast cancer in the DES Action **Voice** five years ago. I am very happy to report that I am doing well, and still cancer free. However, a recent letter in the Lancet¹ reminded me that we still do not know if DES is related to breast cancer among women exposed in utero. This article shared the experiences of two DES daughters, ages 28 and 34, who had recently been diagnosed with breast cancer. My cancer was identified when I was 39 years old.

Currently we do not know if DES exposure in utero is associated with breast cancer. Ongoing research will hopefully settle this question in the near future. We do know, however, that women who took DES while pregnant have a 35% increased risk of developing breast cancer² and that animal studies demonstrate

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Early DES "Research"

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an increased risk of breast cancer for female offspring after exposure to DES³. Since sharing my story five years ago, I have heard of approximately 20 DES daughters who have experienced breast cancer. Most have been in their late thirties or early forties. While this number does not prove an association with DES exposure, it confirms a growing concern among the DES exposed.

We do know that DES daughters are approaching the age of highest risk for developing breast cancer, whether or not it is caused by their exposure to DES. It is critical that all women conduct monthly breast self-exams, receive their annual physical exam by a trained health care practitioner, and receive routine mammograms. PLEASE REMEMBER ALL THREE. I discovered my

tumor during a self exam four months after a routine mammogram, and a repeat mammogram still failed to detect the tumor! Mammograms can detect some tumors before they can be felt, but other tumors can be felt but not seen. This may be especially true in premenopausal women, since their breast tissue is still very dense.

I wish you all the best of health, and encourage you to take steps to protect that health. Cancer is scary, but early detection can lead to a long and healthy life!

I would like to hear from DES daughters who have experienced breast cancer.

- 1. Huckell C, Laskin J, Gelmon K: Premenopausal breast cancer after in-utero exposure to stilboestrol. (letter) *Lancet* 1996; 348: Aug. 3, 1996.
- 2. Colton T, Greenberg R, Noller K, et al: Breast cancer in mothers prescribed stilbestrol in pregnancy: further follow-up. *JAMA* 1993; 269; 2096-2100.
- 3. Bern H, Talamantes F, "Neonatal Mouse Models and Their Relation to Disease in the Human Female," Developmental Effects of Diethylstilbestrol (DES) in Pregnancy, Thieme and Stratton, N.Y., 1981.



VOICE

DES Action Affiliates

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

DES Action/USA National Offices 1615 Broadway, Suite 510 Oakland, CA 94612

California c/o Dr. Wingard Community Medicine M-007 Univ. of Calif-S.D. La Jolla, CA 92093

Box 661653 Los Angeles, CA 90066 652 Cayuga Drive San Jose, CA 95123

Colorado P.O. Box 2645 Colorado Springs, CO 80901

Connecticut Box 131 Guilford, CT 06437

Florida 3931 Venetian Way Tampa, FL 33634-7491

Louisiana P.O. Box 804 Chalmette, LA 70044

Massachusetts P.O. Box 126 Stoughton, MA 02072

Michigan P.O. Box 2692 Ann Arbor, MI 48106 2205 Rosewood SE Grand Rapids, MI 49506

Minnesota Box 3102 Butler Quarter Station

Minneapolis, MN 55403 Missouri 7647 Carswold

7647 Carswold Clayton, MO 63105 New Jersey Box 762

Fort Lee, NJ 07024 Ohio 27060 Cedar Road, #507 Beachwood, OH 44122

Oregon 1050 NE Butler Market Rd. #3 Bend, OR 97701 Pennsylvania Box 398

Nescopeck, PA 18635

Rhode Island 33 Edward Avenue Rumford, RI 02916

Texas 8230 Shadowwood Drive Waco, TX 76712

Washington, D.C. Area 12494 Alexander Cornell Drive Fairfax, VA 22033

> Washington 719-15th Ave. East Seattle, WA 98112

DES Sons Network Michael Freilick 104 Sleepy Hollow Place Cherry Hill, NJ 08003

DES Third Generation Network 10731 Brookley Road Glen Allen, VA 23060

DES Action/Canada National Office 5890 Monkland, Suite 203 Montreal, Quebec H4A 1G2

Alberta 100 Harvest Park Road NE Calgary, AB T3K 4H9

Newfoundland Box 104 Port Aux Basques Newfoundland A0M 1C0

NW Ontario 75 Pine Street Thunder Bay, Ont. P7A 5X2 Ottawa

> Box 35113 Westgate Post Office Ottawa, Ont. K1Z 1A2 **Prince Edward Island**

45 York Lane

Charlottetown, PEI CIA 2A5

Saskatchewan

41 Knowles Crescent

Regina, Sask. S4S 4N9
Toronto
1-800-4821-DES

Vancouver 926 Clements Ave. N. Vancouver, B.C. V7R 2K7

Winnipeg c/o Women's Health Clinic 419 Graham, 3rd Floor Winnipeg, Man. R3C 0H3

DES Action/Australia

P.O. Box 282 Camberwell, Victoria 3124 14 Edmundson Close Thornleigh 2120 NSW

DES Action/Belgium DES Informatiecentrum Kolkensvijverstraat 18 3201 Langdorp, Belgium

DES Action/Britain c/o Women's Health 52 Featherstone Street London EC1 Y 8RT

DES Action/France Info DES/France 9 Allee de Guignegault 45800 St. Jean de Braye

Reseau—DES France 44 Rue Popincourt 75011 Paris

DES Action/Ireland 32 Upper Fitzwilliam St. Dublin 2

DES Action/Italia Centro Simonetta Tosi Casa Intern Donna Via della Lungara 19 00165 Roma

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 a slightly 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.

Published quarterly by DES Action USA 1615 Broadway, # 510 Oakland, CA 94612 (510) 465-4011 FAX: (510) 465-4815 Hotline: 1-800-DES-9288 e-mail: desact@well.com

http://www.desaction.org

Executive Director:
Nora Cody
Board Officers
President:
Amanda Sherman D
VicePresident:
Andrea Goldstein
Secretary:
Karen Lang
Treasurer: Stephanie Kanarek

Contributors: 1 Nora Cody Pat Cody Susan Leavitt Deborah Wingard

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V O I C E

Notes From Nora

Legislative Victories

Lunding for DES Research and Education (passed by Congress in 1992) was set to expire this year, but Senator Tom Harkin and Representative Louise Slaughter are supporting legislation to renew funding through 1999.

DES Action President Amanda Sherman and Program Director Pat Cody attended a recent meeting in Rep. Slaughter's office to discuss the progress in DES research. Scientists from the National Institutes of Health spoke about the importance of continuing to fund research into the health effects of DES. Slaughter, Harkin, and other lawmakers have pledged to support funding in this year's NIH appropriation in the amount of "such sums as may be necessary."

In addition to DES research, we continue our work for a truly national DES education project. DES Action has established a committee to develop a plan for such a national program. We will utilize lessons gleaned from the five regional DES education projects now winding down and from our own many years of experience reaching out to the public and health care providers.

F F F

In our last newsletter (#69) we reported on our efforts to help defeat the "FDA Overhaul Bill." This bill would have drastically weakened the powers of the Food and Drug Administration to regulate consumer products. Fortunately, the bill was killed before Congress ended its session for the year.

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In California, manufacturing and pharmaceutical interests supported a myriad of product liability reform bills that would have greatly restricted consumer access to the courts. I went to our capitol several times to tell our DES story and explain why DES-exposed individuals and other consumers must retain our right to sue for injuries caused by defective products. The Consumer Attorneys of California passed a resolution recognizing and thanking me for my efforts.

We spoke out in Washington, D.C., as well, opposing federal product liability reform efforts. In June our Program Director Pat Cody received a letter from President Clinton on the subject (see reprint, p. 4).

T T T

DES Action's Board of Directors held a busy and productive fall meeting October 5 & 6. The highlight of the weekend was a special dinner held to honor and thank longtime staff person Fay Cohen. A DES mother, Fay has worked in our New York office

(housed at Long Island Jewish Medical Center) for 18 years. Her dedication to the DES community is well-known, and was attested to by the DES daughters who spoke of the invaluable role she had played in their lives. Libby Saks, DES Action Boardmember, remembered Fay's constant query "What about the sons?" as she sought to keep attention on the problems of the little-studied DES sons. We will miss Fay's hard work and humor, and wish her well in all her endeavors.

The board also solidified plans for a special Symposium to be held October 18, 1997 in Boston.

The Symposium will address two questions that we find come up most frequently as we hear from our members:

- What are the implications and possible long-term hazards for a DES daughter taking fertility drugs?
- 2. Is it safe for a DES daughter or a DES mother to take hormone replacement therapy for menopause?

We will keep you posted with further details as we make plans for the Symposium.

In other Board business, elections were held and DES Sons Network Director Michael Freilick (NJ) was reelected, as was former President Karen Fernandes (TX). Kari Christianson (MN) has left the Board after two terms. Karen Lang (WA) was elected Secretary to the Board.

Fall 1996 #

THE WHITE HOUSE WASHINGTON

June 19, 1996

Pat Cody Program Director DES Action 1615 Broadway, Number 510 Oakland, California 94612

Dear Pat:

Thank you for your letter regarding the Product Liability Legal Reform Act of 1996. As I'm sure you know, I vetoed this legislation on May 2.

I believe our legal system needs reform, and I have repeatedly urged Congress to pass limited, meaningful product liability measures. However, I vetoed the product liability bill Congress sent to me because it failed to provide adequate protection either to consumers or to the interests of manufacturers and sellers.

In general, I objected to the bill's "one-way" preemption, which would have imposed federal standards when state law would be more favorable to consumers, but not when state law would be more favorable to manufacturers or sellers. I also had concerns about specific provisions that would have impeded the ability of injured persons to gain fair and adequate recovery.

In particular, I opposed completely eliminating joint liability for noneconomic damages, placing arbitrary caps on punitive damages, and restricting an injured person's right to sue after 15 years without regard to the useful life of the product in question. Additionally, I could not accept the provision that would have limited the rights of third parties who are injured when a person knowingly sells a product to a high-risk customer -- such as when a gun dealer knowingly sells a gun to a convicted felon or a bar owner knowingly serves a drink to a customer who is obviously inebriated.

Congress could have sent me limited, but balanced, product liability reform, and if they had done so, I gladly would have signed the legislation. I appreciate having your advice on this issue, and as I continue working with Congress, I will keep your words in mind.

Sincerely,

Bin Clinton

Take Action

by Susan Leavitt

learned a very important lesson at a seminar I attended. I learned to be proactive. Proactivity is choosing actions based on circumstances. It applies to you, your family, health, and job.

As a 44-year-old DES daughter, I developed a proactive list of things to help me and, hopefully, protect me.

It's so important to know your family's medical history for as many generations as possible. I recently sat with my parents as they dictated our family's medical history to me. We could only go as far back as my maternal great-grandparents and up to my generation that includes two younger sisters. I formatted the history on my computer into a user-friendly chart so that we can all give a copy to our various physicians for our files. I included the relationship to my generation, age at death, cause of death, and ailments for as many relatives as possible. I'll keep it updated as time goes on. Talk with your parents, grandparents, aunts, uncles, and siblings. Include as much information as you can. It's important to trace family medical patterns for the younger generations.

DES daughters, sons, and mothers may need proof of their DES exposure. I was 22 when my mother told me that I was DES exposed. I already knew about DES and wondered if my mother had taken it. To qualify for a new DES study in 1974, I needed proof of my exposure. The only record we could track down was the pharmacy's logbook of the

"Talk with your parents, grandparents, aunts, uncles, and siblings. Include as much information as you can. It's important to trace family medical patterns for the younger generations."

prescription. That was all I needed.

You're even luckier if you get information from your mother's doctor. Do it now! The doctors are getting older. They retire or die and files are destroyed or lost. Find out the name of the doctor who took over your mother's doctor's practice. Find out if the files are still available.

You should see a gynecologist who is well versed in DES examinations, the latest news, and DES history. Ask your doctor to explain terms or procedures. Write down the information while the doctor is speaking with you. Do research on your own. I have a small collection of medical/health books at home. I refer to them constantly. If I don't understand something, I try to find a more technical book and I ask my doctor questions. I've even photocopied pages from technical books and brought them in for my doctor to explain them to me. Doing your own research shows that you're interested in trying to find the answers.

Many years ago I began saving

the labels from my prescriptions. I keep them in a safe place just in case a drug I took is found to cause medical problems. I'll have all of the information I'll need to prove that I took the drug. This includes the date, dosage, physician, and pharmacy.

The easiest thing to do is be prepared when you see your physician—any physician. If you're like me, you're nervous and forgetful. Write notes, questions, and symptoms before your visit. Take notes on what your physician tells you. Keep the notes and responses for easy referral and history. I keep my notes in my planner. I take it to every doctor's appointment and record my blood pressure and anything my doctor tells me including answers to my questions.

Another proactive suggestion is to request a copy of the medical file for you, your spouse, and children.

It only takes a few minutes to do my suggestions. Choose one action that sounds easy to you. Start working on it now. It should give you peace of mind.

Use Donor Option

If you give to the United Way at your place of work, you can specify that your pledge should go to DES Action. Simply find the line on the card marked "donor option" and write in DES Action. If there is not line, or a card has been omitted from your packet, write in "donor option—DES Action."

V O I C E

letters to the editor

Dear Editor:

I am responding to the recent letters in the DES Action Voice from DES daughters with problems with their cornea. I too am a DES daughter with eye problems. However, my disease is not related to the cornea. Rather, it is retinoschisis, a separation of the retina. I was diagnosed with this condition in 1988, and it has resulted in complete loss of part of the vision in my left eye. Have other persons who have been exposed to DES reported similar eye problems? I would be very interested in knowing if there is a connection between DES exposure and difficulties in anatomy of the eye.

Reader, Greenwood SC

Dear Editor:

I am a DES daughter, and have had problems with infertility, two complicated pre-term pregnancies, multiple abnormal Paps, autoimmune problems and now a very unusual aggressive breast cancer. Enough is enough-I feel that DES has been this black cloud haunting every aspect of my life.

The DES newsletters have been very helpful. I can't thank you enough. I feel like a door has been unlocked, at least now I have information about this cloud and know I am not alone.

I am also getting very angry as I read about all the research that hasn't been done. I'm not sure how to deal with this anger in the midst of breast cancer and very aggressive chemo therapy. A part of me wants to sue the DES companies for their complete irresponsibility in follow-up for the mess they created. I would like to talk to anyone who has done a DES lawsuit. I don't need more hassles in my life but I do need a productive way to focus my anger and frustration.

Patti O'Brien South Burlington VT phone 802-865-3494

Your Personal Advocate

Our Winter issue 67 featured an article on managed care, or, the system of using a Health Maintenance Organization (HMO) to cover all medical needs. Since that time we learned about a new group, American Medical Consumers (AMC) set up to act as a patient's representative on an individual basis.

Under the slogan "Health Care is Negotiated Care" this group, headed by Vincent Riccardi M.D., works directly with medical consumers all over the U.S. to ensure that all their rights are respected. AMC provides information, representation, coaching and tutoring, monitoring and guidance. They emphasize the distinction between health care decisions and "benefits" decisions. The old idea that if it was health care

"The old idea that if it was health care related it would be a covered benefit is long gone."

related it would be a covered benefit is long gone. Sad to say, many of us are misinformed to the contrary until the benefit is needed.

For more information on having a Personal Medical Advocate (PMA) you can write or call:

American Medical Consumers 5415 Briggs Ave. La Crescenta CA 91214 phone 818-957-3508 FAX 818-957-4926

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.



book notes

Special Parent, Special Child: Parents of Children with Disabilities Share Their Trials, Triumphs, and Hard-won Wisdom, by Tom Sullivan. Jeremy Tarcher Publishers. Paperback.

he spectrum of disability discussed—cerebral palsy, blindness, life-threatening illness, deafness, learning disability, and Down's syndrome—brings to light a broad array of issues affecting every parent of a special-needs child.

Alternative Medicine: What Works. A comprehensive, easy-to-read review of the Scientific evidence, Pro and Con. by Adriane Fugh-Berman, M.D. Odonion Press, 1996. 225 pages. \$9.00.

r. Fugh-Berman is chair of the National Women's Health Network, and this book covers the effectiveness of over 24 alternative or adjunct treatments. She reports on over 600 studies in clear language.

Early DES "Research"

If you didn't laugh, you'd cry.

Here is an example of the "research" showing that DES was harmless and effective. This is from the British Medical Journal of January 7, 1939. The title is, "Therapeutic Trials of Diethylstilboestrol" by Alfred A. Loeser, M.D. Berlin, L.R.C.P. & S.Ed.

"In the light of the evidence...it appeared well worth while to try this preparation in gynaecological practice.

Tests for Harmlessness

"I first tried the preparation on myself. On the first day I took one tablet of 0.1 mg, on the second day one of 1 mg; on the third day I gave myself an intra-muscular injection of 1 mg., and on the fourth day an injection of 1 mg. in oil solution. There were no unpleasant symptoms or any pain following the injections. Trials were then carried out on...women....

Conclusions

"Diethylstilboestrol shows such marked oestrogenic effects that it has a good substitution action in various forms of ovarian insufficiency. In six of the fifteen cases for which it was used unpleasant secondary effects such as nausea or vomiting were produced."

Confidentiality Assured

As a courtesy to our members, it is our policy that we never sell or rent your names and addresses to any other organization.

phone (





state

Join DES Action!



(510) 465-4011

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

☐ Benefactor: \$1000 and above ☐ Sustainer: \$500 ☐ Associate: \$200	☐ Supporter: \$100 ☐ Friend: \$75 ☐ Subscriber: \$35-\$60 (sliding scale) ☐ Other:	All members receive The DES Action Voice quarterly. Those at the \$100 level and above receive additional annual reports on DES Action's work and progress.		
☐ I am enclosing my annual pa☐ I would like to donate through		rly or □ semi-annual payments totalling \$		
☐ Check enclosed (please make	e payable to: DES Action).			
I am a: DES Daughter 🚨	DES Son □ DES Mother of a □ Daug	ghter □ Son □ Other		
name		DES Action USA		
address			1615 Broadway, Suite 510	

V O I C E

Menopause and hormones

s DES daughters move toward their pre-menopausal years, we receive inquiries almost daily on what research has been done, and on the wisdom of hormone replacement treatment (HRT). The one research article on DES daughters and menopause was in our Spring 1995 issue 64. It covered 296 DES daughters ages 37-39, and reported no indication of early menopause.

We have had a number of articles on menopause, and on HRT. For those readers who have not seen some of these issues, here is a listing of the articles. You can order a copy for \$1 each, or \$2.50 for the entire issue in which it appears.

Issue 35, Winter 1988: Estrogen replacement

Issue 43, Winter 1990: Book reviews on menopause

Issue 47, Winter 1991: Estrogen and breast cancer

Issue 48, Spring 1991: ERT lowers heart disease Issue 54, Fall 1992: Menopause and after

Issue 58, Fall 1993: Estrogens and breast cancer

Issue 60, Spring 1994: Hormone therapy

Issue 61, Summer 1994: Natural remedies for menopause

Issue 65, Summer 1995: Letters on early menopause

Issue 69, Summer 1996: Hormone replacement grows; some experts worried

DES Action USA

National Office 1615 Broadway, Suite 510 Oakland, CA 94612

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