

DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

Issue #21

Summer 1984

Communication from the San Francisco Project

Deciding about Fertility Treatments: Some Considerations

by Judith Turiel, Ed.D.

The Summer, 1983 Voice described a "Partnership for Health" project centered in the San Francisco DES Action office. Funded in early 1983 by the San Francisco Foundation, the James Irvine Foundation, the Henry J. Kaiser Family Foundation, and the Fred Celler Foundation, the project has developed a model in which DES exposed people participate more effectively as consumers of health care by improving access to information and support, and by encouraging productive doctor-patient communication. This report from the project stresses that consumers need to be aware of current medical reports concerning infertility treatments and pregnancy care.

Phone calls and letters to our office suggest that treatment decisions involving fertility and pregnancy are now a fact of life for many DES daughters. Although DES Action does not give medical advice, we do help DES daughters and sons identify current information and questions relevant to their particular decision. When possible, we talk with them about their own or other individuals' experiences of a specific diagnostic procedure or treatment. These calls and letters provide us with valuable insight into medical practices being offered in various communities; often, this information raises questions.

Clomid: Questions Remain

Recently, we have received several inquiries about Clomid (clomiphene citrate). This medication can stimulate ovulation in some women who do not otherwise ovulate. Clomid is also prescribed for an array of fertility problems — including "unexplained infertility" — in the hope that it will produce hormonal activity favorable to conception. (Very simply put, Clomid takes up space on body cells where estrogen should be, "fooling" the brain into reading that more estrogen is needed and sending hormonal signals for increased estrogen production.) For many types of infertility, there is no evidence to support use of Clomid. Like many medications that are effective for certain specific conditions, Clomid may well be over-

prescribed.

Disadvantages of Clomid are routinely mentioned in medical articles; surprisingly, these problems have not always been explained to our callers by their physician. One disadvantage is poor cervical mucus associated with Clomid use. Furthermore, pregnancy rates are relatively low even when Clomid succeeds in inducing ovulation.¹

Alternatives to Clomid are now under investigation, including other medications, and a still experimental "ovulation pump." This portable pump (worn by the woman) is available at a few medical research centers, where it is currently being tested. The pump delivers the needed hormone signal directly (into the vein or under the skin), in pulses timed to mimic daily patterns of a menstrual cycle. Early reports show good results in women with "hypothalamic amenorrhea" and, to a lesser extent, "polycystic ovary-like disease."²

Until improved methods are available for women who do not ovulate, Clomid does offer an increased chance of ovulation and, therefore, pregnancy — a major consideration for these women. Like all medications, Clomid carries some risks; at this point, long term risks for a woman or a child conceived shortly after use of Clomid remain speculative. If you do ovulate on your own, the weighing of Clomid's risks and benefits involves a different balance. Discuss the pros and cons with your doctor: Is there evidence of improved pregnancy rates with Clomid in cases similar to yours? You may also want to discuss reported side-effects with your doctor and with women who have taken Clomid (for example, headaches and depression).

continued page 4

INSIDE

- "I Owe My Life to an Article . . ." p. 3
- Dear Doctor p. 5
- DES Awareness Week Report p. 6

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

Officers, DES Action National:
President: Nancy Adess.

Vice President: Joyce Bichler.

Treasurer: Pat Cody.

Secretary: Kari Christianson.

Editorial Staff: Nancy Adess,
Joyce Bichler, Pat Cody.



Netherlands Group Funded

DES Aktiegroep, our sister chapter in Utrecht, the Netherlands, writes us that they received a three-year government grant for 335,000 guilders (\$118,000) to carry out their program of consumer education. Coordinators Anita Direcks and Ellen t'Hoen have been both working and volunteering with DES Aktiegroep since 1981. They have begun chapters in Amsterdam and Rotterdam, and struggled to receive credibility from the medical profession. Now they report:

We notice a different attitude from doctors. More serious and more willing to listen to us. Some months ago we presented the DES issue for about 50 gynaecologists and they were deeply impressed by our knowledge. Because of your sending of articles we are up to date informed and we still know more than they do... We have plans to translate your *Pregnancy Guide*.

Best of luck to this persistent Dutch group in their continuing work.

Get Into the Action

DES Action National could not have originated and grown without the dedicated efforts of volunteers. Today, we proudly boast the activities of over forty DES Action groups around the country and around the world. The foundation of each group was created and nurtured by volunteers. We still need you.

Write your group today. Offer your services for a few hours a week. Become a part of the action with DES Action.

DES Action/Arizona

Suite #221, P.O. Box 16200
Mesa, AZ 85201

DES Action/California:

P.O. Box 1303
Gardena, CA 90249-0303
1172 Morena Blvd.
San Diego, CA 92110
P.O. Box 1185
Sunnymead, CA 92388
2845 - 24th St.
San Francisco, CA 94110
P.O. Box 481
San Rafael, CA 94902
c/o YMCA, 1122 17th St.
Sacramento, CA 95814

DES Action/Colorado

P.O. Box 2645
Colorado Springs, CO 80901

DES Action/Connecticut

P.O. Box 70
Monroe, CT 06468

DES Action/Georgia

580 Spender Trace
Dunwoody, GA 30338

DES Action/Louisiana

1231 Prytania
New Orleans, LA 70159

DES Action/Massachusetts:

P.O. Box 126

Stoughton, MA 02072

P.O. Box 1043
Northampton, MA 01061

DES Action/Michigan:

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

DES Action/Minnesota:

c/o YWCA, 1130 Nicollet Ave.
Minneapolis, MN 55403

DES Action/Missouri

4712 Milentz
St. Louis, MO 63116

DES Action/New Jersey

P.O. Box 22
Fort Lee, NJ 07024

DES Action/New York:

Long Island Jewish Hospital
New Hyde Park, NY 11040

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

c/o Linda Cain
243 Chelmsford Road
Rochester, NY 14681

P.O. Box 1205
New Paltz, NY 12561

DES Action/Ohio:

P.O. Box 151113
Columbus, OH 43215

P.O. Box 14755
Cleveland, OH 44114
P.O. Box 2691
Akron, OH 44301

DES Action/Oklahoma

P.O. Box 22231
Oklahoma City, OK 73123

DES Action/Oregon

c/o Planned Parenthood
3231 South East 50th Street
Portland, OR 97206

DES Action/Pennsylvania

340 Lenni Road
Glen Riddle, PA 19037

DES Action/Texas

P.O. Box 1635
Friendswood, TX 77546

DES Action/Washington, D.C.

P.O. Box 5311
Rockville, MD 20851

DES Action/Washington

c/o Meschke,
2021 McElroy Place
Puyallup, WA 98371

DES Cancer Network

P.O. Box 10185
Rochester, NY 14610

DES Action/Canada:

c/o Women's Health Clinic
304-414 Graham

Winnipeg,
Manitoba R3C 0L8

Box 311
Greenwood, Nova Scotia
B0P 1N0

7216-33 Avenue
Edmonton, Alberta T6K 1K3

c/o Snowdon, P.O. Box
/C.P. 233
Montreal, Quebec H3X 3T4

P.O. Box 1004, Station A
Toronto, Ontario M5W 1G5

c/o Vancouver Women's
Health Collective
1501 West Broadway
Vancouver, British Columbia
V6J 1W6

DES Action/The Netherlands
DES-Aktiegroep
Maliesingel 46,
3581 BM Utrecht
The Netherlands

DES Action/Australia

P.O. Box 282
Camberwell, Victoria 3124

New Groups Forming

DES Action/Florida

Dorothy Huddleston
3665 Pine St.
Jacksonville, FL 32205

DES Action/Iowa

Kristin Evenson
107 Second Ave., Apt. 3
Coralville, Iowa 52241

DES Action/Nebraska

8105 Howard St.
Omaha, NE 68114

I Owe My Life to an Article My Mother Read . . .

by Vickie Dandridge

Being DES exposed means different things to different people. It has become such a part of my identity that sometimes I resent it. I can't change history but I have found a constructive way of dealing with feelings of frustration and anger. I'm very lucky to be alive and to be able to share my story with you.

Eight years ago my mother (bless her heart) read an article in a women's magazine about DES. She remembered taking the drug because she had had two miscarriages before my brother was born. He is a year older than I and also DES exposed. My mother was reluctant to share an article with me that discussed the possibility of cancer considering my boyfriend had just died of cancer 3 months prior. Thank God she told me.

In order to get an appointment with a DES specialist in the Los Angeles area I had to have documentation that my mother did in fact take DES. After a bit of detective work we found my mother's ob/gyn and the records. The doctor was retired and although very ill was helpful in retrieving the records from her basement.

After filling out numerous forms to be registered in the DESAD project I was ready to be examined. I wasn't nervous. I had spent the previous twelve years in and out of the stirrups for a variety of gyn abnormalities. This was just one more exam as far as I was concerned. When the doctor, after looking a little puzzled, decided that I needed a biopsy, I still wasn't frightened. I had had biopsies in college that weren't all that unpleasant. All in all the exam wasn't bad. I walked away feeling unalarmed.

But when the phone call came about five days later that I needed to come in and discuss the biopsy results with the doctor, I was nervous. Why couldn't I discuss them over the phone? Why wouldn't the receptionist tell me anything or let me speak to the doctor?

I'll never forget walking down the hall toward the doctor's office, clutching my



mother's hand. I had such a cold chill that I knew what we were about to hear wasn't going to be good. The doctor began to tell us that the biopsy results showed "a degree of disease," and that we would have to discuss various forms of treatment to cure the problem.

The "degree of disease" that the doctor so euphemistically referred to was clear cell adenocarcinoma of the vagina. We were in shock. After spending much of the year in and out of oncology wards with my boyfriend, I never thought I would end up on a cancer floor myself. How could I have cancer from a drug that my mother took while pregnant with me? We then rode home trying to digest the news and discussing various treatments, all of which would render me sterile. I remember being more upset about not being able to have children than actually having cancer. I was afraid that I wouldn't be as desirable of a woman if I couldn't have children. My brother came over as soon as I came home. I remember how angry he was when he said, "We should sue those bastards that made that drug!"

Within a month I was recovering from exploratory surgery and anticipating 8 weeks of radiation therapy as well as iridium needle implants in my vagina. My tumor was in an inconvenient location so the doctors felt that radiation was the best way of curing the cancer. After the radiation was over I filed suit against the drug companies. I knew this was going to be a long process and that

the result would be way off in the future. I was very anxious to put all this behind me and to get on with living a normal, happy life.

Then on one of my quarterly follow-up visits to the doctor another biopsy was taken which reported a recurrent malignant tumor. Cancer again? I couldn't believe it. My normal happy life would have to wait. This time around would be much different. I was facing a very serious radical surgery, one that would alter my body's appearance and image forever. It was necessary for my vagina to be reconstructed and my bladder to be removed. I now wear an ostomy appliance. A year after my surgery, my husband and I separated. A year after that my lawsuit came to trial. After my parents and I spent two and a half weeks in trial against the drug companies, we settled out of court with Eli Lilly.

By this time I had been trying to cope with all the surgeries, cancer, doctors' visits, divorce and lawsuits with only my family and friends to help. They love me and have my best interest at heart but no one really knew what I was going through. I had heard of DES Action on and off through the years but was hesitant to get involved for many reasons. I guess denial was probably the biggest reason. I wanted to believe that none of this had changed my life in any way. I wanted my identity not to include being DES exposed and all that goes with it. When I began to show signs of what I consider "battle fatigue", I knew I needed others to talk to who shared similar fears and frustration. As soon as I moved to San Diego I contacted DES Action. After a reassuring conversation with Wendy Horowitz that DES Action was not an alarmist organization full of angry bitter people I was anxious to meet the group.

What I found was a group of loving, supportive, wonderful women dedicated to educating the community on the continuing ramifications of the drug DES. They had all been affected by DES

continued on page 7

Other treatments:

Proceed with caution

Other phone calls and letters ask us about surgery to "correct" uterine malformations, such as the T-shaped uterus seen, by X-ray, in significant numbers of DES daughters. There is no evidence that surgery (called "metroplasty") helps with fertility or pregnancy problems commonly seen in DES daughters. Recent medical journal articles recommend that surgical correction of uterine abnormalities in any woman be considered *only as a last resort*.³

Too often, the pattern for medical therapies is to treat now — often with the best of intentions — and ask questions later. DES exposure itself reflects this problem: an initial lack of adequate studies, followed by continued use of DES as the standard of medical practice, even after scientifically controlled studies revealed no benefit. Ironically, DES exposed men and women may need to be more careful than others to avoid current forms of untested or inappropriately applied medical treatment. DES daughters and sons do require medical surveillance, do experience increased rates of reproductive problems and are, therefore, vulnerable to overtreatment.

In addition, a treatment that appears safe and effective for non-exposed people can result in special problems for a DES exposed person. The medical literature now cautions physicians that cryosurgery and other treatments of the cervix result in significantly more complications in DES daughters than in non-exposed women. The complications include cervical narrowing or obstruction ("stenosis"), which may contribute to infertility and/or menstrual problems.⁴ DES daughters may wish to obtain a second opinion when such treatments are recommended. (For instance, certain forms of "CIN" or "dysplasia" may need careful, ongoing observation rather than treatment; in many cases, these conditions "regress" or disappear, with time.)

Does Your Case Call For Treatment?

Whether prenatal DES exposure increases the likelihood of infertility remains in dispute. For some DES daugh-

ters and sons who are infertile or subfertile, the physiological cause is not always apparent. Any couple considering infertility treatments should remember the importance of tailoring treatment to their particular diagnosis. For some couples, time itself is at least as "effective" as medical intervention. One recent study of pregnancy rates among infertile couples shows a high rate of spontaneous pregnancy (independent of treatment) for certain types of infertility, especially when no cause could be found (called "idiopathic") or post-coital tests revealed inadequate cervical mucus (96% "treatment-independent" pregnancy rate). With diagnosis of endometriosis, Fallopian tube defects, or deficient sperm number or motility, the treatment-independent pregnancy rate was 61%; and with "ovulatory deficiency" (including irregular ovulation, amenorrhea, luteal phase defect), the rate was 44%. In contrast, couples with the more severe conditions of "azoospermia" (absence of sperm in the man's seminal fluid), prolonged amenorrhea (absence of menstruation), or obstruction of both Fallopian tubes in the woman were highly *unlikely* to conceive without appropriate treatment. This *New England Journal of Medicine* report stresses the need for scientific evaluation of the effectiveness of infertility treatments.⁵

What DES Action — and You — Can Do

In conjunction with DES Action National, our locally funded San Francisco project continues to focus on DES-related health care issues — including fertility and pregnancy problems — in order to remain well informed, encourage further research, and convey information between consumers and medical professionals. We survey the medical literature, hold study groups, and consult with physicians at the University of California/San Francisco, and throughout the Bay Area and the United States. Our efforts extend a process reflected in DES Action's *Fertility and Pregnancy Guide for DES Daughters and Sons*, published last fall.* In addition to pre-

*Available from your local DES Action group or from DES Action National.

sending basic information about a range of conditions faced by DES exposed women and men, the *Guide* emphasizes that:

- Information is constantly changing; there are many unknowns, and many medical disagreements regarding diagnosis and treatment.

- In the absence of "answers," each person can try to reach the best decision for her or his own situation, based on the most adequate information available.

- In weighing a treatment's known and unknown risks against its benefits, we must first have evidence that there are benefits. Otherwise, no risks are acceptable.

Individuals vary in their interest, time and comfort with pursuing medical information. Medical journals are available at medical center and many university libraries. If you wish, DES Action can assist you in locating relevant articles. Your doctor should also be a source of current information. She or he may need to search the literature (for example, by using a computer "Medline", through a medical library) for the latest data on success rates of a treatment, its comparison to other and to no treatment, its side effects and contraindications (situations in which a treatment should not be used). You and/or your doctor may want to consult with another doctor experienced in cases similar to yours. Your doctor may be associated with a medical school, or can consult by phone with specialists at a medical center. To expect your doctor to take such steps is reasonable. She or he must be able to obtain the latest information and evaluate that information in light of your particular situation, in a way that makes sense to you.

For many therapies, of course, studies just don't exist, or provide only preliminary information. There may be only individual case reports, the very first hints of possible problems. For example, a recent study of infertile patients with mild endometriosis indicated low rates of pregnancy following treatment with the medication Danazol; the authors suggest reconsidering this standard therapy in a scientifically controlled study.⁶ In addition, a recent case report raises the pos-

continued on page 7

Dear Doctor

A series of questions regarding pregnancy and pregnancy care for DES daughters is answered below by National Advisory Board member Dr. Norma Veridiano. Dr. Veridiano is in practice at the Brookdale Medical Center in New York City, where she sees many DES daughters.

Q. I am DES exposed and thinking about starting a family. I'm nervous about all the problems that I hear are associated with DES exposure and pregnancy. What is the likelihood that I will encounter pregnancy problems?

A. There is no longer any question that a DES exposed female is at definite risk of pregnancy complications. Such complications include increased chance of an extra-uterine pregnancy — also known as ectopic, and also increase of miscarriage and prematurity. We do not, however, discourage our DES patients against pregnancy. A good 85% of this group of women will have at least one full term pregnancy, although it may take them more conceptions to achieve this.

Q. Is there anything I should do or any test I should take before becoming pregnant?

A. Women who have had an untoward pregnancy result should definitely take a Hystrogram test. It is a test whereby a certain dye is injected into the uterus through the cervix and the outline of the uterus and fallopian tubes is visualized by X-Ray. We do not feel it to be necessary for patients who have never become pregnant before to undergo this test, although in our experience we found that we were better able to predict the pregnancy outcome if we have prior knowledge of the shape and size of the uterine cavity.

Q. If I run into problems what can I do? I've heard about something called Cerclage.

A. There are several ways of handling pregnancy complications such as late miscarriages and premature births. Our experience shows that bedrest is one of the most effective methods to prevent such a complication. We have performed Cerclage operations (stitch in the cervix) in the past for patients who had repeated miscarriages in the

4th to 6th month of pregnancy. We do not feel that this procedure should be done for prophylaxis, that is, without definite evidence of an incompetent cervix. We have also found that our results with bedrest compare favorably with the results of Cerclage.

Q. Is it important what services are available at the hospital I choose to go to?

A. I feel that the most important factors that contribute to a successful pregnancy outcome are as follows:

First and foremost is that the Doctor taking care of the exposed pregnant patient is aware of DES related problems, especially those related to impaired reproductive performance. Of equal importance are the facilities available at the hospital where the patient will be confined for care. The availability of a Level 3 Neonatal Unit in the hospital is a requisite. The third factor is the willingness of the patient to abide by the restrictions that may have to be imposed on her during the pregnancy.



The Winter 1983/84 issue of the VOICE included an article on "Progesterone Exposure in Pregnancy." This topic continues to provoke comments and questions from medical professionals and consumers. DES Action recently asked Dr. Robert Glass, faculty member of the University of California at San Francisco Department of Obstetrics, Gynecology and Reproductive Sciences, and co-author of Getting Pregnant in the 1980s (U.C. Press), about his views on progesterone treatment in pregnancy.

Q. A recent article we sent you suggested that a progesterone deficiency may account for miscarriage in some women, and that these women may therefore benefit from receiving progesterone supplements. What do you think?

A. The article did not clarify the basic question of why progesterone levels dropped prior to miscarriage: was this decrease a cause of the miscarriage, or was it a result of the miscarriage? Because the question remains unanswered there is no reason that we should prescribe progesterone for women who have cramping and bleeding during

early pregnancy.

Q. In which cases do you feel progesterone treatment to prevent miscarriage would be warranted?

A. I would use very stringent criteria and would consider treatment with progesterone only if a woman had experienced two or more miscarriages and she showed evidence of an inadequate luteal phase* in 2 menstrual cycles. In those cases, therapy has to be started 2-3 days after ovulation, well before the pregnancy is clinically obvious. There are different causes of an inadequate luteal phase, and some are better treated with drugs other than progesterone.

Q. We've heard from quite a few women who have had progesterone treatment prescribed as a general miscarriage preventative. Why is this happening if we're lacking supporting evidence for its effectiveness?

A. There are many physicians and patients willing to try something if there isn't clear evidence that it's harmful**, and that may be the explanation. In addition, the purported beneficial effects of progesterone in cases of miscarriage and inadequate luteal phase has encouraged individuals to use the medication for prevention of miscarriage even when there is no evidence of hormone deficiency.

Q. Speaking of safety, do you think there is a basis for distinguishing between progesterone (natural) and progestogen (synthetic) when discussing potential risks to the developing fetus?

A. Although many teratologists now feel that the progestogens have been incriminated unfairly in birth defects, I would feel safer using progesterone. I would emphasize that its use should be restricted to the problem of inadequate luteal phase associated with miscarriage (or infertility).

*Luteal phase refers to the period immediately around conception (up through 7 weeks of pregnancy), when hormonal support for the pregnancy is provided primarily by the corpus luteum.

**Note: DES Action advocates placing emphasis on proven safety of prospective treatments, rather than on "lack of evidence of harm".

Send your questions to "Dear Doctor", DES Action Voice, 109 Plains Road, New Paltz, NY 12561.

As a result of this extensive attention, our national office and local affiliates have been kept busy answering the more than 5,000 people who have written to request information about DES exposure.

continued

sibility of persistent amenorrhea (no menstrual periods) in some women following Danazol treatment for endometriosis.⁷

Your doctor should not be offended by your inquiries about current studies. Nor should we, as patients, be worried about offending a physician by our efforts at finding out what is and is not known, where there is medical disagreement, what another doctor would recommend. For most of the health conditions faced by DES exposed and non-exposed people, there are no medical "truths", only informed decisions about probable outcomes and individual priorities — a health care process you and your provider need to work out together.

Postscript

Remember, most DES daughters who wish to become pregnant will succeed. Since DES daughters do have increased risk of preterm labor, a brief note on betamimetic drugs (for example, ritodrine and terbutaline), commonly given to stop preterm labor: Maternal side effects of these medications, when given intravenously in the hospital, are well documented; however, little information is available about oral forms — pills taken at home, usually after hospital treatment. A recent case report of serious cardiovascular (heart, blood pressure) side effects with oral terbutaline states,

Patients should be . . . advised that if they begin to experience any severe [symptom], especially chest pains, shortness of breath, or [loss of con-

sciousness (fainting)], immediate evaluation in a hospital setting is mandated.⁸

A case report, of course, reflects only one case. However, the very point of potentially serious, unforeseen individual reactions to a medication taken at home, with no direct surveillance by a nurse or doctor, means that "only one case" is enough for patients and doctors to be alerted about early warning signs. More on pregnancy in future *Voice* issues.

Thank you to Dr. Eldon Schriock (University of California at San Francisco, soon to be at University of Tennessee, Memphis) for reviewing the contents of this article.

Footnotes

1. For example, see Roumen, F. et al in *Fertility and Sterility*, vol. 41 (February 1984) p. 237. Includes references to additional articles on Clomid.
2. Recent reports include: *Obstetrical and Gynecological Survey*, May 1984; *Fertility and Sterility*, March 1983 (article by S. Yen) and October 1983 (two articles

on ovulation pump); *New England Journal of Medicine*, April 26, 1984 (article by Hurley et al, p. 1069); *American Journal of Obstetrics and Gynecology*, April 1, 1984 (article by Loucopoulos et al, p. 895).

3. Abramovici, H. et al, *International Journal of Fertility*, vol. 28 (1983), p. 161; Heinonen, P. and Pystynen, P., *Fertility and Sterility*, vol. 40 (September 1983) p. 311.
4. Haney, A. and Hammond, M., *Journal of Reproductive Medicine*, vol. 28 (December 1983), p. 851; Schmidt, G. and Fowler, W., *Obstetrics and Gynecology*, vol. 56 (September 1980) p. 333; Stillman, R., *Fertility and Sterility*, vol. 41 (March 1984) p. 369.
5. For definitions of categories and diagnoses used in this study, see Collins, J. et al, *New England Journal of Medicine*, vol. 309 (November 17, 1983) p. 1201.
6. Butler, L. et al, *Fertility and Sterility*, vol. 41 (March 1984) p. 373.
7. Peress, M., *Fertility and Sterility*, vol. 41 (February 1984) p. 322.
8. Carpenter and Decuir, *American Journal of Obstetrics and Gynecology*, vol. 148 (March 15, 1984) p. 821.

I Owe My Life . . . continued from page 4
in their own way. They were nervous about doctor appointments, like I was. They were tearful and fearful of their fertility and infertility like I was. They were also amazed at how much of the population was still unaware of the DES problem. I wanted to be a part of an organization which had the potential of saving lives by alerting people to ask their mothers if they were exposed to DES. I owe my life to an article my mother read in a women's magazine. Media coverage has a special impor-

tance in my life. Who knows how long DES is going to affect our lives? Subscribing to the *DES Action Voice* is a sure way of monitoring the effects this drug has on our lives in the years to come. I've seen what supporting your local chapter can do for your community as well as for your own support and well-being.

Dealing with feelings of anger and bitterness has been difficult these last few years. My association with *DES Action* has helped me direct those feelings in a constructive and positive direction.

SUPPORT DES ACTION!

Enclosed is my tax-deductible gift. (Make checks payable to **DES Action** and mail to:
Long Island Jewish-Hillside Medical Center, New Hyde Park, NY 11040)

- | | |
|--|---|
| <input type="checkbox"/> Subscriber: \$15-\$25 | Receives subscription to the <i>DES Action Voice</i> quarterly newsletter. |
| <input type="checkbox"/> Friend: \$50-\$250 | Receives the <i>Voice</i> plus Joyce Bichler's book, <i>DES Daughter</i> . |
| <input type="checkbox"/> Supporter: over \$250 | Receives all of the above plus annual reports on the organization's progress. |

name _____

address _____

city/state/zip _____

I am a ☐ DES Daughter ☐ DES Son ☐ DES Mother

Letters to the Editor

Dear Editor:

I have ordered several back issues of DES Action Voice and have become a subscriber. Since I have learned of the DES Action group and have been so kindly replied to at my last inquiry, I don't feel so alone or afraid. Thank you so much for your interest and contribution to those of us who have been exposed. In a society where we are constantly bombarded with new health threats daily, it is encouraging to know that there is an organization that is making a positive impact to rectify past errors.

Sincerely yours,
Subscriber
Anchorage, AK

Dear DES Action:

I am a DES daughter. Because of my exposure to DES and the subsequent damage to my fallopian tubes and uterus, I will probably never be able to carry a child. This letter is just to say thank-you. While I was struggling with the emotional pain of acceptance and feeling quite alone it was comforting just to have your newsletter arrive and remind me that I was in fact *not* alone.

I wish that I could afford to send more than \$25, but I hope this will help if only in a small way.

Your program has helped and informed me. I wish you continued success in your efforts.

Gratefully,
Subscriber
Charlestown, RI

Dear Editor:

After reading the Spring newsletter I felt that I needed to voice my concerns. I have known that I am a DES daughter for 10 years . . . I have seen doctors for infertility for four and a half years and have yet to talk with a doctor who will even consider the DES exposure relating to the infertility. I wonder how many more women are receiving the advice that I have? It seems the medical profession is failing to educate themselves on the subject of DES.

I would appreciate it if literature could be sent to the staff of the three clinics at which I have seen physicians in the last four years. I am very concerned that many doctors are telling their patients, "DES is nothing to be concerned about" as I have heard many times!

Sincerely,
Subscriber
Trego, WI

Ed. note: DES Action has sent information as requested. We hope this enlightens your doctors.

**Remember someone with a
DES Action Special Tribute donation.**

DES Action National

West Coast Office: 2845 24th Street, San Francisco, CA 94110

ADDRESS CORRECTION REQUESTED

Non-Profit
Organization
US POSTAGE

PAID

PERMIT NO. 14081
SAN FRANCISCO, CA

Moving? Please let us know.

