

DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

Vol. 4, No. 1

Summer 1982

From the President

Fear or Facts?

I received a disturbing note recently from a physician. According to his answer on a referral questionnaire we had sent him, he examines about ten DES daughters a year. He wrote, "More time should go to convincing them [DES daughters] of their *normalcy*. You people frighten me! I will accept your referrals but will *downplay* the condition."

I wondered, for perhaps the 500th time, if we do frighten people by constantly urging them to find out if they are DES mothers, daughters, or sons, and by insisting that DES-exposed people, and especially DES daughters, have frequent examinations by knowledgeable physicians.

The following day, I received a copy of a recent medical article, sent by one of our Medical Advisory Board physicians. The article, discussed in this issue (page 6), describes the case histories of two young

women in their early 20s, each of whom had been having regular, routine examinations for six years and two years, respectively. Now each of them had developed vaginal cancer. In both cases, the cancer had *not* been detected by a Pap smear, even after the Pap smear was directed to the very spot where the physician had felt a lump!

Until now, many physicians and researchers have declared that clear cell cancer had never developed in a DES daughter under observation. In other words, they felt that the cancer was either there on the first visit to the doctor, or would not develop at all. Now we know otherwise. That's why we've been urging DES daughters to be vigilant in their semi-annual check-ups with DES-knowledgeable physicians. We knew that all the facts weren't in, that all the research wasn't yet done.

I talk almost daily with young women who have experienced some type of problem having children of their own, most likely related to their DES exposure. Some have been unable to become pregnant at all. Others—many—have had miscarriages or premature babies. Thanks to research of the last few years, young women who know they were exposed to DES can avoid some of these problems by receiving more intensive pre-natal care than other women who are not considered "high risk" during their pregnancies.

Until now, physicians would not check for possible miscarriage in what seemed to be a normal pregnancy, unless there had been a miscarriage before. Now we know that DES daughters should have frequent pre-natal examinations for possible "incompetent cervix," and that in some instances, miscarriage may be avoided.

Do we frighten people? Or do we give them the information they need to take the best care of themselves?

You be the judge.

—Nancy Adess

People Talking to People . . .

Have you told everyone you know about DES? Have you told neighbors and friends, relatives and acquaintances?

More than half of those exposed to DES *still don't know it*. One way of reaching them all with the information they need is by *people talking to people*.

We find, especially, that people don't talk about DES very much to sons or husbands. True, there hasn't been as much medical research on sons as on the daughters, but we *do* know that DES sons need to know who they are in case they, too, have medical problems, or if they have trouble fathering children.

So, talk about DES. Talk to your social club, your PTA, your church or synagogue group, as well as to your neighbors, relatives, and friends. (If you want help in doing this, ask your local DES Action group or DES Action National.)

And tell them about the DES Action Voice so they, too, can keep up to date on all the latest DES news.

Thanks for your help in spreading the word.

—N.A.

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Is There a DES Action in Your Community?

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

DES find out about their exposure and the care they need.

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

DES Action/California:

1638B Haight St.
San Francisco, CA 94117
P.O. Box 205
195 Claremont Ave.
Long Beach, CA 90803
P.O. Box 1185
Sunnymead, CA 92388
1172 Morena Blvd.
San Diego, CA 92110
c/o YMCA, 1122 17th St.
Sacramento, CA 95814

DES Action/Florida

9586 Portside Drive
Seminole, FL 33542

DES Action/Hawaii

95-710 Kipapa Dr., #15
Mililani Town, HI 96789

DES Action/Illinois

P.O. Box 173
Park Forest, IL 60466

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 2692
Ann Arbor, MI 48106
2205 Rosewood SE
Grand Rapids, MI 49506

DES Action/Minnesota:

626 12th Ave.
Two Harbors, MN 55616
c/o YWCA, 1130 Nicollet Ave.
Minneapolis, MN 55403

DES Action/Montana

c/o Tester, Rt. 1, P.O. Box 2950
Arlee, MT 59821

DES Action/Nevada

P.O. Box 5748
Reno, NV 89513

DES Action/New Hampshire

RD 2, Turtle Island Road
Wolfeboro, NH 03894

DES Action/New Jersey

P.O. Box 323
Westwood, NJ 07675

DES Action/New Mexico

306 Mesa SE
Albuquerque, NM 87106

DES Action/New York

Long Island Jewish Hospital
New Hyde Park, NY 11040

DES Action/Ohio

P.O. Box 151113
Columbus, OH 43215

DES Action/Oregon

P.O. Box 12092
Portland, OR 97212

DES Action/Pennsylvania

340 Lenni Rd.
Glen Riddle, PA 19037

DES Action/Tennessee

4104 McCahill Road
Chattanooga, TN 37415

DES Action/Texas

P.O. Box 1596
Spring, TX 77373

DES Action/Wisconsin

821 W. St. Francis
De Pere, WI 54115

DES Action/Washington, D.C.

P.O. Box 5311
Rockville, MD 20851

DES Action/Washington:

c/o Meschke, 2021 McElroy Place
Puyallup, WA 98371
2707 E. 18th St.
Spokane, WA 99203

DES and the Military

by Eloise Engle Paananen

Although we are all aware that DES exposure was rampant among the civilian population, not much has been revealed about that segment of our society that marches to the tune of our military bands—and our military doctors. If you think you're out of the woods because the gold braid and oak leaf cluster blessed you, you'd better take another look. DES was dispensed in the military just as widely as any place else, and if you figure your medical records will be easy to come by, just try to get them.

Ironically, I was married to a Navy doctor at the time I was exposed to DES. I had had two miscarriages, and when spotting began in my next pregnancy, I was given massive doses of stilbestrol (DES) and put to bed in hopes of saving the current fetus. The baby boy was born and seemed just fine; needless to say, I was overjoyed. Six months later I was pregnant again, and again given massive doses of DES. This time I had a girl.

All seemed all right until my daughter reached her 15th birthday. Then, after two days of nausea and vomiting, she was rushed to the Long Beach Naval Hospital. During surgery the doctors found an ovarian cyst. This puzzled them, as they had never seen this kind of tumor in a girl so young. They removed it, along with a portion of the fallopian tube, and as her medical records indicate, "Patient recovered normally."

But not quite. Since that time, my daughter has joined the ranks of millions of DES-exposed young women who have adenosis and other abnormalities. She has been in and out of the hospital and doctors' offices for extensive examinations and treatment for excessive bleeding. The exams will be a part of her life from now on.

Continued on page 7

Granting News

We are pleased to announce that a generous grant of \$5,000 from the L.J. Skaggs and Mary C. Skaggs Foundation in Oakland, California, augmented subscribers' donations to make the Linda Kelsey Public Service Announcements

available to all local DES Action groups. DES Action National has also received a grant of \$3,000 from the Chevron Corporation Headquarters in San Francisco through the San Francisco Foundation.

The **DES Action Voice** is published quarterly by DES Action National, Inc.
Officers, DES Action, National:
President: Nancy Adess. Vice President: Dolores Wallgren. Treasurer: Pat Cody. Secretary: Libby Saks.
Editorial Staff: Susan White, Nancy Adess, Pat Cody, Judy Turiel, Joanne Derbort.

DES Daughter: The Final Chapter?

by Joyce Bichler

It was 11:30 a.m. on May 11th. An ordinary day: I was in my office with two clients discussing their concerns regarding the needs of their elderly mother. Although my door was closed I could faintly make out the voice of my husband drifting in from the outer room of the Social Service office. Curious, I concluded my conversation and made an appointment to continue our meeting the following day. As they departed I followed them out and came face to face with my husband. Mike was holding a bouquet of flowers in one hand and a large box in the other. I was puzzled. Mike instructed me to look in the box. As I lifted the cover I saw a cake with the words WE WON! written across the top. The tears rolled down my face at the realization that the long, hard battle was coming to a close. Mike and I embraced to the cheers of my co-workers.

Apparently the plaintiff was the last to know—Mike had gotten a call from someone who heard the news on the radio! Within moments of Mike's arrival, my attorney, Alfred Julien of the New York law firm Julien, Schlesinger & Finz, called to inform me officially that the New York State Court of Appeals had unanimously upheld the verdict in Bichler vs. Lilly. The courts of New York conclusively verified that DES was not properly tested before being given to



pregnant women, that it caused my cancer and (in a precedent-setting move) that Eli Lilly & Co. could be held accountable even though I, like so many other DES-exposed, could not prove that it was a Lilly product my mother had taken. In essence, the highest court in New York unanimously declared that DES victims are not to be continually victimized; that we who have suffered do have recourse; that those who were negligent must be accountable.

Was it possible that the draining, near-

breaking fight was over? My initial reaction was relief—the tensions, the stress, the seemingly never-ending war was finally put to rest. Joy took its place.

Several days have now passed since word of the precedent-setting verdict arrived. The good feelings are still there but also the realization that there are more battles to be won. My legal suit is now "settled." I have the satisfaction of having fought back, and because of the brilliance of my attorneys, Alfred Julien and Leonard Finz, I can proudly say we won. But other battles for the DES-exposed continue. The path should now be easier and swifter for many others who seek legal redress, but the ultimate DES fight has not changed. Millions of people still do not know they were exposed; DES daughters continue to have pregnancy problems; DES sons and mothers still are left with many questions about their exposure; many are still trying to find DES-informed physicians. We must all keep working and looking towards a time when all DES-exposed are identified and getting the proper care. Research must continue. Information must be disseminated. Professionals must be trained. We can only rest when, as consumers, we know that tragedies like DES can *never, ever* happen again!

I can only hope that this case has brought us one step closer to that goal.

Personal View

DES—It's Everyone's Issue

by Kim Klein

I am sure you have all heard stories or read in history books about child labor—the way children were sent into mines at the age of five or six, or the way they were worked in factories for nine and ten hours a day for a pittance. Even though it is unlikely that anyone reading this article worked under such conditions, we all understand why those conditions must never be repeated. In the same way, we understand abolition, or the need for pasteurized milk, or polio vaccines. We don't need personal, direct experience of something to know the meaning of it in our own lives and in our society.

So I am always surprised when people ask me why I am so deeply involved in DES Action National. I have worked with DES Action for the past three years, and last year it was my pleasure to accept a position on the National Board of Directors. I spend ten to fifteen hours each month fundraising and doing outreach on the subject of DES. Yet I am not DES exposed, nor is anyone in my family. As a result of working on the DES issue, I now have close friends who are DES exposed.

DES is everyone's issue. It is my issue because I could easily have been a DES

daughter, and it is just by chance that I am not, and that thousands more people are not DES daughters, sons, or mothers.

Even though I was not exposed to DES, I was exposed to numerous other substances, many of which are equally harmful, have been put on the market without being tested properly, and have been promoted and advertised despite potential hazards. For example, many thousands of women used the Dalkon Shield IUD which was removed from the market for the extremely harmful effects it was found to have. Millions of others

The Psychological Impact of Infertility, Miscarriage, Stillbirth, and Premature Delivery

by Nechama Liss-Levinson, Ph.D.

Most people are aware of the contribution of psychology to the area of child development. There are many theories regarding the various stages through which children pass on their way to adult development. In addition, we are inundated with information regarding the effects of parenting. Should one breast or bottle feed? Is discipline a necessary evil or a positive good?

Only recently have psychologists turned the looking glass around and begun to examine the stages in the lives of the parents.

Most psychologists agree that having children is a crisis in the marital relationship, one in which all of the roles and all of the rules change. In truth, the crisis begins earlier than the actual birth. The beginnings are present in the decision to try to have children. For any couple, this decision is fraught with anxiety. For the DES couple, the anxiety is heightened by concerns about possible difficulties related to DES exposure.

Studies do seem to show a small increase in the percentage of DES-exposed women who have miscarriages, stillborns, and premature deliveries. Some seem to report an increase in infertility for both women and men, although this is not as clearly documented. It is important to realize that the percentages of DES-exposed individuals experiencing these problems is small.*

Nevertheless, I feel that it's important to discuss these issues. They are very meaningful, and not small, to those who are affected.

* *Editor's note:* Dr. Herbst's 1981 study on DES daughters and reproduction found that about 50% of daughters had trouble carrying a first pregnancy to term, although 81% did eventually have a child. He also found more DES daughters unable to conceive, and a greater percentage than normal who did conceive had tubal pregnancies. See *DES Action Voice*, vol. 3, no. 4, Spring 1982.

What follows is a discussion of the psychological impact of infertility, miscarriage and stillbirth, and premature delivery. It is important to keep in mind that there are many ways to respond to a crisis. The general reactions discussed here are common reactions. They are not meant to be implied as "correct," and you may not experience these reactions. Knowing what the range of more common responses is, however, may help you in confronting your own feelings. What is most important is to be able to recognize and express your own feelings—whatever they may be.

Infertility

The success of contraception in our society has resulted in a generation which expects conception once contraception is removed. When this does not happen, many assumptions about oneself are challenged. Your own identity, particularly your sexual identity as a man or a woman, may seem to be at stake.

In the past, the silence and secrecy surrounding infertility compounded the problems it presented.

Although you may know all of the facts concerning infertility, you may still believe in your heart that only through a successful pregnancy can you prove your womanhood, or adulthood.

In addition, there may be tension between the couple over fault—whose "fault" is this anyway? The pressures may be increased by unwelcome comments by others, well meaning and otherwise. Further, many DES mothers may feel that they will be cleared of all "guilt" when their daughters produce healthy progeny.

In the past, the silence and secrecy surrounding infertility compounded the problems it presented. This silence is being replaced by knowledge. There are more and better treatments for infertility, and support groups, such as RESOLVE, help couples to share their feelings with one another.

One final issue regarding fertility problems, which is difficult for the DES couple in particular, is the very nature of some of the treatments suggested to "cure" the problem. Often the physician will suggest medications or hormones to increase the chances of a pregnancy, thus calling up the spectre of DES. The couple needs to evaluate carefully the pros and cons in light of their own situation. There is no one answer for everyone.

Miscarriages and Stillbirth

A disproportionately high number of DES daughters have had miscarriages and stillborns. This difficult situation is often worsened by the reluctance of anyone—professional staff or personal friends and relatives—to acknowledge the event. People are generally saddened and frightened by the birth of a stillborn, and would prefer that the whole event just disappear without a trace. The parents, on the other hand, have a real need to grieve and mourn their loss. Those who advise the couple "that it was for the best," "that something was probably wrong with the fetus," or that they can "try again" are missing the essential reality of the situation. The couple needs a chance to mourn the loss of their child, and their dreams for that child.

Some hospitals have recently begun training their staff to deal with this kind of loss, and have instituted policies which facilitate the mourning process. The policies may include: encouraging parents to see or touch the stillborn, encouraging

Support Groups Fill Unmet Needs

One of the workshops best liked at last October's Annual Meeting was on holding Support Groups for DES-exposed people.

At the meeting, we set aside time to hold support groups with each other—one for daughters, another for mothers—and to talk about the best ways to run support groups for others. In fact, we became so involved in *being* a support group that we didn't talk much about the "how to."

When thinking about starting a support group for DES-exposed people, the following questions provide a helpful starting point:

- Why do people join a support/information group?
- What needs can the group fulfill? (for example, crisis support, ongoing support, information about latest research and treatment, information and support for legal actions).
- What are the limits of a group like this? It's important to distinguish between offering support and making sure people get appropriate care from professionals. For example, some individuals may need more sustained, professional psychological help, others may need medical recommendations.
- What structure should the group have: should there be specific topics or open-ended discussion? How long should each meeting be? How often should it meet? Should there be a facilitator? Should someone be appointed to jot down questions that come up?
- Should mothers and daughters meet separately? What might the differences be between them? What about a group for teenagers?
- What topics would be most important to cover; such as the risk and fears of cancer, problems with fertility and pregnancy, what constitutes a thorough exam, mother-daughter relationships, legal actions, treatments for dysplasia, infertility, cancer.

Answers to these questions depend on the needs of your group, which will probably change with time.



One Example

We talked about how the San Francisco Support Group got started, as one example.

In San Francisco, the DES Action group decided to start a support/discussion group for two main reasons: 1) we never had time at business meetings to talk about our questions and feelings; and 2) we wanted to be better educated about our health care so we could ask questions when we went to the doctor and get the information we need.

Three people with a range of personal concerns and experiences decided to start the group, and invited others to join. The experiences of the three initial participants included problems with infertility and pregnancy, dysplasia, and basic concerns about DES exams.

To encourage others to attend, we mailed an invitation to everyone who had contacted our office during the past six months, explaining the purpose of the group and when the first meeting would be. Other ways to involve people would be to send notices to newspapers, put up flyers, etc.

Twelve women came to the first meeting, where we decided that we would meet for four sessions and then talk at the end of that time about whether we wanted to continue.

At the first session we spent most of the time with introductions and talking about our most urgent concerns. It was a time to begin to feel comfortable with discussing these personal matters with each other.

The second session included a presentation by one of our core group (a DES daughter who is also a nurse), describing in detail a complete DES exam. She used pictures and gave a very thorough description. This meeting was a huge success. People were fascinated by being able to talk about the exam without feeling rushed, as they often do at their exams, and with the advantage of not having to be going through the exam at the time!

Other sessions dealt with infertility and with legal issues, alternating with sessions of open-ended talk.

At the end of each meeting we informally reviewed how we felt the group was going, and members used this time to report on recent experiences and changes in their lives. In particular, many reported that they felt they were participating more actively in their medical care.

At the end of the fourth meeting, we filled out more formal evaluation forms to give us a sense of how well we met people's expectations.

Now it's up to the group to provide its own structure, decide how often to meet, and on what topics.

Our evaluation told us that DES daughters want both information (facts) and support. Talking with others who could understand their situation and feelings was vital. The support group meetings filled the needs for information and for sharing that they could not have gotten anywhere else.

—N.A.

parents to name the stillborn and have a burial for the dead baby, encouraging family and friends to talk about the event, and providing facts for the family to alleviate some of the unnecessary guilt which this event may generate.

For any woman who miscarries or gives birth to a stillborn, there are questions she may ask herself, all unrelated to the reality of the event. What did I do wrong which caused this to happen? Should I have taken it easy more often? Did I jog too much? Should I not have eaten in that restaurant? Should I not have lifted that heavy bag? For the DES family, the guilt which is commonly felt may be intensified, and may interfere with the grieving process. The potential grandmother, the DES mother, may blame herself for her daughter's misfortune. The daughter, who has a need to mourn, may feel that she must hide her feelings from her mother, at a time when she really needs her mother's support. Being aware of these issues as a family is the first step towards resolving them.

Premature Babies

In the past dozen years we have learned a great deal about the psychological impact of having a premature baby. Klaus and Kennel, a team of physicians working with premature infants and their families, found that it is most helpful to encourage some positive form of interaction between even the youngest premature infant and his or her parents. Most hospitals with neonatal intensive care units have policies which encourage this interaction. They may have unlimited visiting for the parents of premature babies. They may encourage the parents to touch or hold their infants, and when possible to feed them, or to express breast milk for the baby. Even small amounts of contact have been shown to have long-term positive results.

For the parents of the premature infant, however, there are weeks, and sometimes months, of uncertainty. In a time when you expected to be rejoicing and celebrating, you may be unsure of how to respond. The tension generated may affect the husband-wife relationship, or relationships with the child's

grandparents. The constant questioning by well-meaning others can become burdensome, overwhelming, rather than the help it was meant to be. People may appear to be Pollyanna-ish, telling you how wonderful it is that your child was born now when there is so much medical help available, while inside you are wondering how they can consider you lucky at all. Or you may be feeling very optimistic, only to find that others don't visit you, or don't bring presents for your baby, out of the uncertainty as to whether the baby will survive this critical period.

Again, inter-generational conflict may develop around guilt-related issues. The demands on the young parents are enormous. And the strain which can arise due to a grandmother thinking that she has caused all of this is an aggravation of an already difficult situation.

Conclusions

Whether the situation is infertility, miscarriage or stillbirth, or premature birth, there is the additional problem of a sense of isolation. You may be uncomfortable around people who don't seem to be having trouble having children, or uncomfortable being around their healthy children. You may wonder, "Why did this happen to me?" You may rage inside, "It just isn't fair!" And, in truth, it isn't.

There are no easy answers to these dilemmas. But the first important task is for the couple to become aware of these issues, to realize the problems and tensions which may arise as secondary problems, and to begin talking about them to one another, or to other couples in similar situations.

Although the possibility of inter-generational conflict has been mentioned a number of times, there is also the possibility of developing a new level of closeness and intimacy with one's own mother during this time. After all, in all probability, one's own mother experienced some pregnancy-related difficulties, whether it was miscarriage, or stillbirth, or some other problem. She may be able to relate quite well to what you are experiencing. And if you haven't already done so, it may be the right time to air your mutual feelings regarding DES, and for your mother to relieve herself of any guilt, once and for all.

For the couple, these problems are just some of the many trials which you face together. Meeting this challenge may help strengthen your relationship, and even deepen your love for one another.

Ms. Liss-Levinson is Psychological Consultant to the Long Island DES Screening Center.

Medical Abstract

"Development of Clear Cell Adenocarcinoma in DES-Exposed Offspring Under Observation," Kaufman, et. al. *Obstetrics and Gynecology*, Vol. 59, No. 6 (Supp.), June 1982.

This case report of two DES daughters in the DESAD study at Baylor College of Medicine, Houston, describes the onset of cancer in patients whose initial examinations were negative. One patient was in the study for two years before cancer was diagnosed at age 23. The second, age 22, had been in the study for nearly six years. In both cases, the cancers were

first noted by palpation, and, because the clear-cell nodules were below the skin, Pap smears were negative.

This report confirms the importance of careful palpation in DES screening. The authors state, "The current report, as well as those by Anderson et al. and Veridiano et al.*, reemphasize the fact that cancer can develop in these young women at any time and that careful, continuous observation is necessary in their management."

*DES Action Voice, vol. 3, no. 1

Military, continued from page 2.

My son developed epididymal cysts, common in males with DES exposure. He is unmarried, so he doesn't know whether he can father a child, but he is aware that he must be checked regularly by knowledgeable urologists.

As a doctor's wife, I knew what was being given to me at the time of my pregnancies, but I had blind faith and I followed orders. Many military wives don't know whether or not they were given DES. DES Action recommends that as a first step military wives who were exposed, or suspect they may have been exposed, to DES get hold of their medical records. Here's how you do it:

For active duty members, write to the National Personnel Records Center (Military), 9700 Page Blvd., St. Louis, MO 63132. These records are retained for 50 years. Dependent personnel may obtain

copies of their inpatient and outpatient records from the National Personnel Center (Civilian), 111 Winnebago St., St. Louis, MO 63118. These records are retained for 25 years. Former active duty members of the Air Force and Navy should put "AF" or "Navy" in the Page Blvd. address.

Requests should include the following information:

- * Name or place where treatment was obtained;

- * Approximate dates of treatment, including date of last treatment at military facility;

- * Sponsor's name, rank and Social Security number or Service Number at time of treatment;

- * Authorization for release of information for adults, signed by persons who received treatment; for minors, signed

by parent or guardian; for deceased, signed by next of kin;

- * Identity of record requested—inpatient or outpatient or both;

- * Name and address of medical facility or physician to whom copies are sent, if so desired.

The total number of exposed military dependents is unknown. No specific military-wide policy has been established for examination of DES-exposed mothers or offspring. No studies have been made on DES-exposed mothers, sons or daughters. The Navy spokesman I talked with said, "It is our opinion that there have been a large number of such patients evaluated as individuals."

Think back. If you were with the military and had any problems with pregnancy, you probably got your share of DES. Better check on it.

Everyone's Issue, from page 3.

have used birth control pills, now reported not to be totally safe. For myself, it is quite likely that the ceiling of my high school was made with asbestos fibers, and the area of California where I live has been repeatedly sprayed with the controversial pesticide malathion. My former boss used to lend me his Ford Pinto to do errands, and I live near radioactive toxic waste dumps. I could go on listing things I have either been exposed to or barely missed, but the point is simple: the diseases and deaths that have resulted from these substances and numerous others like them come as a result of putting profits before people. This sometimes benign and sometimes callous disregard for human life is too much a feature of our modern-day existence.

Furthermore, there may be drugs on the market now that could be the DES of the future. And more drugs, devices and products will be marketed and will harm people before this decade is over.

Like many of us, I have few hours in a week that I can volunteer my time. So I have chosen carefully among the many organizations and issues that are important to me. DES Action National brings together my commitment to work in the area of health care, on an issue with broad ramifications, and with an organization that does its job competently and uses its resources wisely.

Reaching people exposed to DES involves talking to thousands of people who are not exposed. Both those who are and those who aren't have an opportunity to learn what they can do to become more canny consumers, more

demanding in their choice of medical care providers, and more involved in their own health care.

DES Action brings together people of all ages, races and both sexes. We work with doctors, nurses and other health care providers. Our members are housewives, social workers, lawyers, students, teachers, construction workers, cooks, and all kinds of people united to find all DES-exposed people and give them the medical information and care they need.

DES is not limited to those directly affected by it. DES affects all of us. Through my efforts and those of thousands of people like me, both DES exposed and not, consumers are beginning to have all the information we need in order to make conscientious choices about our health care, and to insure that the DES story will not be repeated.

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, N.Y. 11040)

☐ 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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Letters to the Editor

Dear Editor:

I would like to share my 11-year-old daughter's school composition with other parents of young DES-exposed children:

My Greatest Experience with My Mother

When my mother was pregnant, she took DES (Diethylstilbestrol) to prevent miscarriage. I became a DES daughter.

My mother is a volunteer at DES Action, a non-profit organization, helping DES daughters and sons find doctors and information.

When she first told me about DES, I felt confused, anxious, alone, curious. I had many questions, one of them, why did she take DES? (It was given to two to six million women.)

And she said she wanted *me* badly! That meant a lot!

S.W.
New York



Did You Know?

If you give to the United Way at your place of work, you can earmark part or all of your pledge to *DES Action National*. Simply find the line or the card marked "Donor Option" and write *DES Action National*. If there is no line, or a card had been omitted from your packet, write in *Donor Option—DES Action National*.

(Not every county has a donor option plan. Contact your local United Way, or ask your United Way representative for information about your county.)

When the pledge comes to the National office, your local DES Action group will be given credit for your donation, just as with a subscription to the *Voice*. DES Action National and its local chapters are not United Way agencies or affiliates, but as a health organization, DES Action is able to participate in this Donor Option Plan. Please let us know if you designate us as your United Way pledge recipient, so we can mark our records.

DES Action National

West Coast Office: 1638-B Haight Street San Francisco, CA 94117

ADDRESS CORRECTION REQUESTED

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ARE YOU MOVING?

Please let DES ACTION know of your new address, so we can make sure you keep receiving your DES ACTION *Voice*. *Thank You!*

