

DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

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Fall 1982

Reproductive Health

Endometriosis

Endometriosis—the presence of uterine tissue outside the uterus—is a disease we hear more and more about in young women. Although popular literature has referred to it as the “working woman’s disease,” characterizing the woman with endometriosis as childless and career-oriented, in fact endometriosis has been known in women of all lifestyles.

DES Action receives many questions about endometriosis from DES daughters. No research has evaluated a causal link between DES exposure and endometriosis, but because it is increasingly prevalent in young women and in DES daughters, we decided to reprint parts of a recent article about it from the Santa Cruz (California) Women’s Health Center Newsletter of June, 1982.

By definition, endometriosis is the presence of endometrial tissue outside the uterus. Tissue most commonly “implants” in the pelvic cavity, the ovaries, uterine ligaments, the fallopian tubes and the colon. Less frequently, “implants” are found as far away as the lungs.

The problem with endometrial tissue clinging to sites other than the uterus is that, under the influence of the reproductive hormones, implants cyclically proliferate and bleed just as in the uterus. They are usually located where there is inadequate space for growth and no outlet for the blood. The body reacts with pain and the formation of scar tissue, which in more advanced cases creates distentions and adhesions of the pelvic organs, as well as more intense pain. Women with endometriosis may experience, either cyclically or chronically, dysmenorrhea (painful periods), dyspareunia (painful intercourse), painful defecation, backaches, abdominal cramping, nausea or vomiting. Oddly enough, some women with advanced endometriosis experience only mild pain or none at all; the reverse is also true.

Besides pain, the main “complication” of endometriosis is infertility. Endometriosis is discovered in approximately 30% of women who are being evaluated for infertility.¹ Figures vary widely, but anywhere from 40% to 75% of women with endometriosis cannot become pregnant.² It appears that the further advanced

the condition, the greater the incidence of infertility. This most likely results from the obstruction of different reproductive organs, which hinders the motility of either the egg or the sperm.

Several theories partially explain endometriosis’ origin, the most widely accepted being that endometrial tissue migrates from the uterus to other sites by means of “retrograde” menstruation. Various studies confirm that in as many as 50% of women examined during surgery, menstrual blood does indeed flow backwards up and out of the fallopian tubes, carrying bits of endometrial tissue into the pelvic cavity.³ It is not known why these bits of tissue occasionally implant. Nor is it known for certain whether tampons or the smaller cervical openings in childless women encourage retrograde bleeding.

Other theories state that implants travel by means of the lymph system or bloodstream. Also, it is thought that cells present at birth can transform into active endometrial tissue during adulthood.⁴

Because the symptoms of endometriosis are easily confused with those of other common medical problems, many women have gone undiagnosed and improperly treated for years. Painful periods from bleeding implants are often considered simple dysmenorrhea. Endometriosis is usually distinguished from dysmenorrhea by beginning 5–7 days before the menses, peaking at the time of maximum flow and persisting throughout the period or beyond. The pain may be less cramplike and constant, located in the area of the implants rather than in the uterus alone. Painful intercourse, constipation, chronic pelvic pain and infertility have numerous causes, and endometriosis is seldom initially suspected.

continued on page 2

INSIDE

Product Liability Bill Update	p. 5
From DES Daughter to Premie Parent	p. 3
DES Action: A Nursing Action—And Yours! . . .	p. 6

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:

1638-B 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

P.O. Box 6841
New Orleans, LA 70174

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
Wolfboro, NH 03894

DES Action/New Jersey

P.O. Box 22
Fort Lee, NJ 07024

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 Road
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

New Groups Organizing

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

Missouri: Cheryl Hermann, 4712 Milentz, St. Louis, MO 63116

North Carolina: Sherri Hopkins, 7512 Park Vista Circle, Pineville, NC 28134

New Hampshire: Maureen Ireland, RFD #1, Epsom, NH 03234

Quebec: Snowdon, P.O. Box 233, Montreal, Quebec, Canada, H3X 374.

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President: Nancy Adess. Vice President: Dolores Wallgren. Treasurer: Pat Cody. Secretary: Libby Saks.

Editorial Staff: Nancy Adess, Pat Cody, Joanne Derbort, Dolores Wallgren.

Endometriosis, continued from page 1.

The first step out of the mire of vague, multiple symptoms and inappropriate treatments is an absolute diagnosis of endometriosis. A thorough health history, along with a pelvic and rectal exam, are important but cannot establish a definitive diagnosis. (Aching which lasts several days after an exam may suggest endometriosis.)

In recent years laparoscopy has replaced nearly all other diagnostic methods. Laparoscopy requires two small incisions made in the abdomen so that a slim lighted tube may be inserted to visually examine the pelvic cavity. Implants may be removed and biopsied to confirm diagnosis.

Unfortunately, laparoscopy is expensive (around \$1500 including outpatient hospital charges) but it can profoundly relieve the years of anxiety about the nature of a woman's pain and can eliminate the risks and expense of inappropriate or unnecessary treatments.

Effective treatments for endometriosis range from aspirin to hysterectomies. Aspirin or drugs such as Motrin provide relief in mild cases but do not prevent the growth or spread of implants. In more advanced cases, hormonal therapy is often recommended. Hormones relieve pain in approximately 80% of women by suppressing cyclic endometrial engorgement and shedding. Continuous hormone therapy for 6-9 months with birth control pills high in progesterone or Danazol (a weakened "male hormone") causes implants to regress, degenerate and be reabsorbed. Statistics as to the permanency of the degeneration are not available. Danazol seems to be the most effective and consequently the most popular treatment. Temporary side effects include: weight gain, edema, mild virilization (hair growth and voice deepening) and menopausal symptoms.

Pregnancy and lengthy lactation are recommended as "natural hormonal therapy," causing implant regression for varying lengths of time. However, given different lifestyles and goals, many women do not consider a prescription for pregnancy an acceptable remedy for relief. If pregnancy is desired, it is a bitter irony that pregnancy is often hard to achieve with endometriosis.

continued next page

From DES Daughter to Preemie Parent

by Carol Simpson

It was during a September 1979 hurricane on Cape Cod that Dale and I decided to stop using birth control. Two factors entered into our decision: my age (28) and my mother's recent diagnosis of breast cancer. I was determined that she have a grandchild before her death.

The subsequent months crawled by, and disappointment grew into anguish. I had been working with DES Action/Washington since March 1978, and had read every article, heard every horror story on infertility among DES daughters. And my mother had had many pregnancy problems (which is why she took DES when pregnant with me). I wrote away for information on adoption. My doctor saw me in March of 1981 and said we could begin testing any time I was ready. Dale had a urological exam and was pronounced fertile. We took an anniversary trip to the mountains—everyone said relaxing would help. It didn't.

But on June 1, 1981, the news I had been waiting to hear for so long was a reality—"You're pregnant!" Almost immediately, the spotting began. Less than 2 weeks later, while watching a DES Action colleague on TV, I passed a large amount of blood, and my husband sped home from work to take me to the doctor. Luckily, it was only an endocervical polyp that had engorged with the increased vascularity of pregnancy. Another hurdle was cleared.

The next few months were uneventful. I had a busy summer working with DES Action, appearing on TV and radio and trying to keep up with the resulting phone calls. My mother appeared to take a turn for the better after hearing our good news. She began collecting baby clothes—all for a girl.

On October 30, I was interviewed for a local newspaper on how it felt to be a pregnant DES daughter. I was a little more than 6 months along, and said to the reporter, "I seem to be past the danger point—I'm optimistic that I'll

have no problems." Little did I know that in less than 4 hours I would be in the hospital; my water broke as I stood in a department store near my home.

The next two days were spent in bed, praying that the baby would not have to be born so early. The nurses and my obstetrician had such positive attitudes that I remained calm, at least on the outside. My mother had entered a New England hospital the week before—her cancer had spread to her brain, and I didn't want her to worry about me as well.

Both of the symptoms that necessitated the baby's birth—a fever and onset of labor—occurred on the afternoon of November 1. At 10 p.m. my doctor told Dale and me that a C-section was necessary due to the baby's small size as seen on sonogram. Her head could not withstand the pressure of a vaginal delivery.

At 10:54 p.m., Elizabeth Cady Simpson emerged, tiny and red. We were
continued on page 4

Endometriosis, continued

To overcome fertility complications, hormonal therapy is the generally recommended first step. In one study, Danazol increased the fertility rate from 46.4% to 72.2%. If laparoscopy shows cysts, scar tissue or distortions of the pelvic organs, conservative corrective surgery is needed. Such surgery shows a 50%–80% cure rate in relieving pain and correcting infertility.

Complete hysterectomy with removal of all implants in the abdominal cavity is an effective treatment for advanced disease. However, this procedure eliminates hormonal cycling and reproductive potential and should be used only after other methods have been tried. It should be noted that endometriosis is rarely fatal with or without treatment.

Women with endometriosis need to keep updated on research findings, to consult with physicians who specialize in pelvic pain or endometriosis, and, most importantly, to disregard the current media deluge which trivializes and sensationalizes this serious disease. An Endometriosis Association was formed

in 1980 to collect and disseminate information, and they can be contacted at 2654 N. 112th St., Milwaukee, WI 53226.

—Deborah Abbott

FOOTNOTES

1–4 *Current Obstetric and Gynecologic Diagnosis and Treatment*, Benson & Associates, Lange Medical Publications, 1980.

OTHER REFERENCES

New Hampshire Women's Health Center Newsletter

Various articles provided by and with thanks to the Endometriosis Association.

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Warning on Talcum Powder

Women who regularly use talcum powder in the genital area and on sanitary napkins have a more than three times greater risk of ovarian cancer, according to an article on "Ovarian Cancer and Talc" in *Cancer*, July 15, 1982.

In a study by Cramer, et al., 215 white women with epithelial ovarian cancer (average age 53) were compared with a control group of 215 women from the general population. Of the cancer patients, 42.8% regularly used talc either as a dusting powder on the genital area, or on sanitary napkins, compared with 28.4% of the control group. Women who used talcum powder in one of these ways were almost twice as likely to develop ovarian cancer. Women who regularly used talc for both purposes had more than three times the risk of ovarian cancer compared to women who did not use talc at all. The article concludes, "This provides some support for an association between talc and ovarian cancer hypothesized because of the similarity of ovarian cancer to mesotheliomas and the chemical relation of talc to asbestos, a known cause of mesotheliomas. . . . The mineral talc is . . . chemically related to several asbestos group minerals and occurring in nature with them. Generic 'talc' is seldom pure and may be contaminated with asbestos, particularly in powders formulated prior to 1976."

fortunate that she weighed 3 lbs. 2 oz., large for 27–28 weeks gestation. By 7:30 a.m., the Milk Bank nurse was in my room, teaching me to use the breast pump (I grew to despise its whirring and impersonal plastic tubes over the months to come). I saw Elizabeth for the first time amidst IVs, a respirator and several nurses and doctors. Dale and I were shocked at her thinness, but thought she was beautiful nonetheless.

The following days and weeks became an emotional roller coaster ride. Elizabeth's condition improved and worsened; old problems resolved, new ones cropped up. She endured a collapsed lung, a "hole" in her heart, and respiratory distress. Her weight plummeted to 2 lbs. 9 oz. The most serious problem occurred during a minor surgical procedure—a severe bleeding into her brain cavity. In order to try and remove the resulting clot which plugged her spinal cord, daily spinal taps and then head taps were performed for over 2 months. Neither procedure worked, and finally, to avoid hydrocephalus ("water on the brain"), a shunt (a tube which allows fluid to drain into the abdominal cavity) was put in. Three days later, at 11 weeks of age and weighing 5

lbs. 6 oz., Elizabeth came home to stay.

Unfortunately, on December 3, my mother had died. She had always attributed her cancer to DES. She was never able to see Elizabeth, nor did I see Mom conscious after an August visit. She did know that she had a beautiful granddaughter, and to this day, when Elizabeth smiles or looks at me lovingly, I am crushed to realize that Mom will never see her.

The prognosis for Elizabeth has always been uncertain. Her hemorrhage was severe, and there is a chance that she will be handicapped and/or retarded. But at 9 months of age and 16 pounds, Elizabeth is able to do everything a 6- or 7-month old full-term infant can do, and has shown only some muscular stiffness in her legs (something her weekly physical therapy should easily cure). She may have trouble with speech or have a learning disability later in life, but right now we are thrilled with her progress.

Sometimes a tragedy in one's life can turn a positive direction. Dale and I went through the lowest of lows last winter, and we're closer for it. And now we've been instrumental in the formation of a support group for parents of preemies. I was convinced of the effectiveness of such a group after my long affiliation with DES Action. We also

knew that as wonderful as the doctors and nurses were to us, nothing could replace the communication from parents who had "been there" and survived. Our group is now writing a brochure for new Intensive Care Nursery parents, offering babysitting and rides to the hospital, over-the-phone support, and a reading list. I have already been able to help a couple decide to allow their child to have a shunt—when they saw Elizabeth and how alert and active she is, they realized that a shunt is not as frightening as it sounds.

I know there is a good chance that Elizabeth's prematurity and resultant problems were caused by my DES exposure and that it could happen again. I am angry at that thought, that my daughter has gone through more pain in less than a year than most people go through in a lifetime, and at a \$70,000+ hospital bill. But Dale and I are not excluding the possibility of having another child. My doctor is optimistic about my chances of carrying a second baby to full term. Our future, then, is uncertain, but with the support we have, we feel we can accomplish almost anything. And Elizabeth is a miracle and a joy!

For more information on starting a preemie parent group, write to me c/o DES Action/Washington, P.O. Box 5311, Rockville, MD 20851.

Support for Infertility

Meet "Resolve, Inc."

RESOLVE, Inc., is a national, non-profit organization that offers counseling, support groups, and information and referral for couples experiencing problems of infertility. There are now chapters in 40 states. Many of our members are DES daughters or sons

which members can talk with someone else who has shared their experiences; for example, a woman with DES exposure can share her experience of a hysterosalpingogram or the emotional pain of pregnancy loss with another woman with similar experiences.

couples typically have about their infertility problems and appropriate treatment.

In this time of heightened public awareness of the problems of DES exposure, as well as the concerns of infertile couples, we at RESOLVE plan to

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who are now experiencing reproductive problems. RESOLVE's national staff maintains up-to-date information on medical referrals and on relevant medical testing and treatment for the DES-exposed as well as for other specialized problems of infertility. RESOLVE also maintains a "contact network" through

By writing or calling the national offices of RESOLVE, Inc., in Belmont, Mass., an individual or couple can join RESOLVE and receive the newsletter published five times a year, information on contacting local chapters, and a listing of fact sheets and books on infertility which answer many of the questions

continue working with DES Action and other groups to get quality services and support for the millions of individuals and couples affected. If you would like to be in touch with RESOLVE, write to P.O. Box 474, Belmont, MA 02178, or call (617) 484-2424 Monday through Friday, 9 a.m. to 4 p.m.

a letter to Oregon Senator Bob Packwood, Chair of the Senate Commerce Committee, indicating that a federal product liability law would “add insult to injury by depriving consumers of the ability to protect themselves.”

Reproduced here is Representative Waxman's response to a DES Action member's letter, making clear his opposition to the current legislation.



DES Action: A Nursing Action—And Yours!

by Peggy Swanson Conner

DES Action has become a very important part of my life, but not for reasons many people would think. I am not DES-exposed, nor are the other members of my family.

A year ago, I read a book called *DES Daughter*, by Joyce Bichler, and was shaken by the pain of her experience with a "time bomb"—exposure to the "miracle drug" diethylstilbestrol—which blew up years later. As a woman, I was deeply affected; her truth was part of my nightmares and even daytime fears, and I questioned my ability to deal with such an experience sanely at the age of twenty-eight, much less at eighteen. Yet, because I am also a student nurse, I began to think about others who might be DES-exposed. How many were, or are, unaware of their exposure? How many believe, as Joyce did, that they are the only ones with problems of which most of our society is still unaware? Was there anyone in my community who might not know that he or she had been DES-exposed, or thought that there was no one with whom to share feelings and experiences? If so, I wondered, how could I reach them? More important, would I really be able to be of assistance if I did find someone? Would that person be able to find answers to questions, or even emotional support, if needed?

Many of my own questions were answered through trips to libraries, calls to various public service agencies, and in conversations with several different health care professionals. As I learned about the history and uses of DES and other synthetic and natural hormones and read published results of clinical and laboratory discoveries concerning DES exposure, it became evident that there were no community services equipped to inform the public of possible risks from DES exposure. It struck me that I seemed to be as well as or better informed on the subject than most others I encountered in health care. Yet, was there a need? How could I locate those, if any, in my area who might be DES-exposed?

Remembering the addresses of DES Action offices Joyce had provided at the end of her book, I wrote to one of them,

requesting information and advice. I also realized that organizing a branch of DES Action and notifying the local media of this new source of public information and service might help me determine the need for that service. Both the media and the public response were wonderful. All the local television stations cooperated to produce a very tasteful announcement, complete with "dub-in" of my telephone number for viewers to call. Radio stations and newspapers later provided coverage of basic facts about DES, and about the place and date for the first public meeting I arranged.

I became involved in DES Action for the same reasons I decided to go into nursing...



The first meeting of the Chattanooga branch of DES Action was held on November 22, 1981. I was nervous at that meeting, yet I knew that I wasn't really alone. Another student from my class had come to the meeting, and I had the support of my family, teachers, and my advisers from DES Action, National. In the course of several lengthy long-distance phone calls, National Board members guided, encouraged,

and praised me, and listened to my efforts, questions, doubts, and fears. They knew from experience that I, a new leader and support-giver, needed leadership and support myself. As I was also in the middle of a semester, my teachers and family worked with me, helping me find the time needed to give to something they saw as being important to me, as well as important in itself.

What has happened in our new group since the first meeting? We are still small; some members have dropped out, others have joined us. We have formed strong bonds of friendship while working for the goals we all seem to share concerning DES Action. Between work, caring for our families, going to school, and even being involved in other community activities, we all find the time for "conference" calls, monthly meetings, fund-raising sales, and making plans for future events, such as having booths at local "health fairs," sponsoring a DES-oriented seminar, and initiating a "DES Awareness Week," hopefully by the end of next year. These plans, we believe, will help us reach our goals of contacting and assisting everyone in our area who is DES-exposed.

I became involved in DES Action for the same reasons I decided to go into nursing—to be a part of meeting people's needs, especially health needs, and show caring in the best way I can. To me, the goals and activities of DES Action, National are nursing actions any of us can do, no matter what our career choices, or whether we are DES-exposed or non-exposed. If we wish to inform ourselves, and then share this information, we can all be part of meeting people's needs. Perhaps we could be better prepared to listen to a friend, or encourage them to have regular medical supervision by a physician knowledgeable of the effects and signs of DES exposure. Perhaps, by sharing information, giving referrals, and encouraging regular health care attention to DES-related problems, we could help in the early detection of clear-cell adenocarcinoma in one young woman. Isn't that one young woman worth the time?

DES ACTION VOICE

Back Issues of the DES Action Voice

Back issues are available for **\$2.00 each**. Please indicate issues desired.
Make checks payable to **DES Action**, Long Island Jewish Hospital, New Hyde Park, NY 11040

Volume 1 (1979-80)

No. 1

Federal DES Task Force and DESAD study
Approval withdrawn for DES in animal feed
DES exposure and urogenital disorders in males
The colposcope

No. 2

Editorial: Cancer risk among DES daughters
The DES exposed woman and her gynecologist
Medical Abstract: Report from the DESAD project
Legal Review: Defense lawyers fight over strategy in DES cases

No. 3

Editorial: DES daughters and the pill
First DES lawsuit won
DES daughters: Beware of mammography
DES exposure found to affect pregnancy
Obtaining military records
The laser
Medical Abstracts: Fertility in DES exposed offspring; Risk factors for testicular cancer in young men
Dear Doctor: Endometriosis; Adenosis

No. 4

Pregnancy outcome in DES offspring
Personal Views: DES daughters and mothers; DES daughter and husband share concerns
Medical Abstracts: DES sons
Dear Doctor: DES daughters and infertility

Volume 2 (1980-81)

No. 1

Editorial: DES daughters and pregnancy
Personal Views: A DES son's story; A daughter reaches out
Warning on cryosurgery
Medical Abstracts: DES daughters and pregnancy outcome
Dear Doctor: Precocious puberty in DES daughters; Adenosis and sexual intercourse; DES exposure late in pregnancy

No. 2

Editorial: DES daughters and cancer screening
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Medical Abstract: Psychological impact of DES exposure
Dear Doctor: Progesterone exposure; Effects on non-exposed siblings
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How to obtain medical records
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Dear Doctor: Natural family planning; Endometriosis

No. 4

Description of the DES screening exam
Issues facing parents of 9-14-year-old DES daughters
Personal View: Health insurance—another hurdle
Major DES legal victory: Bichler vs. Eli Lilly
Letter to the Editor: Vitamin E and cystic breasts

Volume 3 (1981-82)

No. 1

Maternity care for DES daughters: Physician's view and patient's experience
Book Review: *DES Daughter* by Joyce Bichler
Guidelines for DES daughters with dysplasia
Personal View: A 12-year-old's first exam
Bibliography: Titles of 30 important DES research articles
Medical Abstracts: Delayed onset of cancer in DES daughters; Upper genital tract changes and pregnancy outcome in DES daughters

No. 2

Book Review: *DES: The Complete Story* by Cynthia Orenburg
Reference Text for Physicians: *Developmental Effects of DES in Pregnancy* by Arthur Herbst, M.D., and Howard Bern, Ph.D.
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Dear Doctor: Ultrasound to rule out ectopic pregnancy
Letter to the Editor: Testicular cancer and testicular self-exams

No. 3

Book Review: *When Pregnancy Fails* by Susan Borg and Judith Lasker
Planning a DES Action public meeting
Personal View: Participating in the DESAD study
Information for DES sons
Glossary of DES-related terminology
Medical Abstracts: Some DES daughters have withered tubes; Cancer in pregnancy

No. 4

Editorial: Putting DES exposure in perspective
Tace and DES daughters
Legal and legislative updates
Medical Abstract: Reproductive experience in DES daughters

Volume 4 (1982)

No. 1

Editorial: Fear or facts
DES and the Military
DES Daughter—The final chapter?
DES—It's everyone's issue
The psychological impact of problems with pregnancy
Medical Abstract: Clear cell carcinoma in DES daughters under observation

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address _____

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

Interviewing DES-Exposed People

by Robert Meyers

I began to realize the widespread nature of the DES phenomenon in this country when I began telling friends and colleagues about my latest book project. Many of them began telling me, in return, that they were DES-exposed, or thought they might be. After a number of these conversations, I realized that the stories of America's three generations of DES people would be at the heart of my book.

The book was shaped by the personal experiences of the DES population. I illustrated every medical phenomenon—pregnancy problems, psychological impact—with a story about real people. So many women gave me horror stories of callous treatment at the hands of physicians as they sought information and help about DES exposure that I created a chapter on "medical callousness."

As a professional journalist, I had no problem asking women intimate questions about their medical histories, per-

sonal circumstances, and the social impact DES exposure had had on their lives. But as a man, I discovered that my initial questions of DES sons were timid, thin, and inconsequential. I was shying away from asking men the difficult questions I had asked of women because I was afraid of what the consequences might have been for me had my mother taken DES.

Once I was over that hurdle, I went back to all of my original male subjects, and asked the tough questions that I had been previously afraid to ask, to make their interviews as comprehensive as the interviews with DES women had been.

I wanted as vivid and candid a series of personal stories as possible, to bring home the fact that drugs like DES do not exist in a vacuum, but enter the bloodstreams and living rooms of millions of people.

Sometimes by accident, sometimes by request, I interviewed family members independently of each other. A

number of them later wrote to say that they had not realized their daughter/mother/father/son felt a certain way, until they read the manuscript.

On a number of occasions, DES daughters, or sons, or mothers, or fathers, assured me that some other family member was too grief-stricken, or guilt-ridden, or too upset, to be of much use as an interview subject; when I contacted these other family members, however, I almost always found them articulate, compassionate, intelligent—and willing to talk. What I had stumbled on was the transference of emotions from one party to another.

Hundreds of people from around the country—including people in London and Paris, where I traveled for historical research—many of them members of DES Action, helped me in my work. It was a labor of love for all of us.

Robert Meyers' latest book, DES: The Bitter Pill, will be published next spring by Putnam.

DES Action National

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