

DES Research Symposium: Looking Back, Looking Ahead

Thanks to a grant from the Sumner T. McKnight Foundation, we are able to sponsor an all-day research and discussion conference in Minneapolis this year on Friday, October 20, the day before our Annual Conference.

Candy Tedeschi, RNC, a national Board member, who works at the DES Screening Clinic, L.I.J. Medical Center, will begin the session with a talk on "DES: The Basics." She will be followed by Kenneth Noller, M.D., Director, DESAD Project, and Professor and Chairman of the Dept. of Obstetrics and Gynecology, University of Massachusetts Medical School, on "Immune System Effects: What Do We Know?"

In the afternoon, Arthur Haney, M.D., Director, Reproductive Endocrinology and



Kenneth Noller, M.D.



Arthur Haney, M.D.



Sidney Wolfe, M.D.

Infertility, Duke University Medical Center, will speak on "Fertility Issues," and the day will conclude with Sidney Wolfe, M.D., Director, Health Research Group (affiliated with Ralph Nader), speaking on "Where Do We Go From Here?" There will be time for questions and discussion from the floor after each speaker.

This symposium is independent from the Annual Conference.

It is open to anyone, and those attending will need to make their own travel and lodging arrangements. The registration fee of \$25 includes lunch, and registrants will get a list of hotels and other details by writing to our Symposium Committee, DES Action MN, Box 3102 Butler Quarter Station, Minneapolis, MN 55403. Space is limited, so it's wise to register early.

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Choosing Non-Parenthood

By Ellen 't Hoen, DES Aktiegroep, The Netherlands

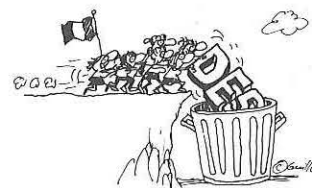
Our society is family oriented. People are supposed to live in families. Man, woman and children is still the future blueprint for many young people. The picture of the happy family and the role of the woman in this is presented to us

in many ways. Commercials on television show us the cozy, happy home in which the family lives. Women's magazines write about pregnancy, child care and how to be a good wife and mother, despite the fact that reality

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Get Into Action

DES Action USA could not have originated and grown without the dedicated efforts of volunteers. Today, we proudly boast the activities of over forty DES Action groups across 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.



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The European Parliament has passed a resolution on the use of DES and the effects on the users and their children. While the Parliament is advisory and does not have the power that a national Parliament or Congress has, its importance in influencing the 12 member nations is growing because in 1992 all these countries will form one economic unit of over 300 million people.

In recent action promoted by our Netherlands DES Aktiegroep with the aid of the "Greens" environmental sector, the European Parliament called on their European Commission to start a public information campaign for both the medical profession and the public. The Parliament has also asked the Commission to:

- Document the extent of European use of DES during pregnancy;
- Initiate a European registry for research on hormonal transplacental carcinogenesis;
- Adopt measures to prevent the production of DES and its export to the Third World;
- Ascertain which member states still use DES and for what purposes;
- Coordinate a program for identifying and informing the DES exposed;
- Ensure the labeling with a non-verbal symbol of pharmaceutical products whose safety for use in pregnancy has not been established.

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DES Fathers Speak

By Martha Cotiaux

It has always been hard for me to talk to my husband about our daughter's exposure to DES. My expressions of fear and rage were met with his non-verbal shrugs of despair. DES became a subject I felt he didn't want to talk about. Similar feelings were expressed by my friend Ruth Hirshberg as we shared many feelings during numerous trips up to Albany to fight for the repeal of New York's statute of limitations law. Concern for DES victims seemed to be "women's work"—as evidenced by the multitudes of women (and absence of men) in Albany.

Then one day, as Ruth and I were scheduled to appear on a local TV show, my husband said to me, "Why doesn't anybody ever ask the DES father how he feels?" This took me by surprise. My reply was to ask him to put his feelings on paper. Here is his response:

"How does a father of a DES daughter react? When we first discussed that my wife, Martha, had had DES prescribed during her pregnancy and that there were possible side effects to our daughter, the problem was in its early stages. Little was really known and much less was said. Consulting the attending doctors led to the "really no concern" answers. Martha didn't let it rest—questioning, reading, probing until she got satisfying answers. Then the potential magnitude of the problem and its possible effects on our daughter's health became a horrible reality. Examination by DES

specialists determined her condition to show the classic complications of DES exposure and that she must be continually monitored for any change in condition for the rest of her life.

"The unknown fear of what would continually lie ahead for this beautiful child, growing toward womanhood with so many uncertainties and such grave possibilities, would be in my mind daily.

"Perhaps the problem that was even greater than dealing with my daughter's physical condition was watching the guilt that Martha had taken on herself. The punishment inflicted daily, hourly, on what she perceived she had done to her child. The pain never really left. The fear of what might lie ahead still doesn't go away—and my pain is not being able to help. One can rationalize: you follow doctor's advice, you could not possibly know, you did what you were told was best. Rationalizing that does not help a mother's guilt and fears.

"Do I say, 'I, too, worry. I fear. I hurt.'? Will this help Martha or make the situation worse? Should I be strong? Should I cry? I fear for my child. I anguish for my wife. I can never know what is still to come for my child—for her children. I do know there will never be complete peace for me."

Reading my husband's response was a very moving experience for me. I feel that many DES fathers must have locked-in feelings that their wives have misinterpreted. When I talked to

Ruth's husband Allan he responded with the following:

"My feeling as a DES father is a cautious feeling of apprehension which escalates at the time my daughter goes to her annual physical. I have great concern regarding her ability to have children. I also have a feeling of anger at a system that allows drugs such as DES to be marketed without adequate testing."

Another father that I talked to, who wished to remain anonymous, was concerned with the guilt that he felt the DES mother lives with. A fatalist, he accepts what can't be changed, but is furious that the greed to make money could lead the drug companies to take such a tragic course.

When I discussed a desire to talk to several other DES fathers, their wives were quick to say they couldn't easily talk to their husbands about DES and they were sure that their husbands wouldn't want to be questioned about it for an article. Perhaps because women have always assumed the role of the family caretaker, and the fact that the DES mother feels such a personal responsibility for taking the prescribed medication, she has misinterpreted the father's grim acceptance as a lack of concern. Many DES mothers share so many similar experiences; lack of communication with the father may be one of them. We would like to hear from other DES fathers in response to this article, to print in further VOICE issues.



CHOICE *continued from page 1.* . shows that for (mainly) women, the family is sometimes not a safe or pleasant place to be. The pressure to start a family is everywhere.

Child or career

Many girls will answer the question, "What do you want to be when you grow up?" with "a mother." However, a number of these girls will never become mothers. A large group of women choose, for various reasons, not to have children, and are perfectly happy about it. Young women realize that having a child often means choosing not to have a career. In the Netherlands, 80% of the women who have a child stop working. Not always voluntarily—but because there are very few provisions for women with children to keep their jobs. There is lack of day-care for children, lack of part-time jobs. The more interesting, promising and better paid jobs are hardly available on a part-time basis. Women who do try to combine having a job and having children find themselves spending their salaries on baby-sitters. Women who want to go back to work after the children go to school have a hard time finding a job and picking up their initial career.

It is often, despite good intentions, in practice very difficult to share taking care of the children with a male partner. Men are not used to working part-time. There are also no part-time jobs available for them. Also, men as a group do not demand changes in this situation in order to meet their responsibilities in taking care of the children. There is a long way to go before we will

achieve a situation in which men and women come to a fair division of labour. This issue remains a "women's issue" whether we want it or not. A Dutch female politician once said: "The man completes the integration of work and family by putting a picture of his wife and children on his desk." Obviously, this situation makes many women hesitate to have children.

To choose or not to choose

Aside from the reasons above, there may be other considerations in choosing non-parent-hood. Some women choose not to have children because they do not want them. Others, because they know they are at risk for problems and do not want to live through anxieties that go with a high risk pregnancy and the risks for the baby. Women who have gone through a number of fertility treatments may reach a point at which they do not want to go any further with the treatments despite the fact that new reproductive technologies are offered. After all, these procedures mean in many cases putting your life on hold, postponing making future plans, until a pregnancy is achieved. For some women it is a relief to finally decide to stop the many hospital visits and monthly tension and anxiety and disappointment when a period takes away the hope. In some cases the decision for non-parent-hood is an almost accidental one ("I have always known that I did not want to have children and never gave it much thought"), in other cases one that is taken, less voluntarily, with pain and grief.

"One day it will be too late"

Regardless of her decision, a

woman in her childbearing years is constantly addressed as a potential mother. A woman's identity seems to be dependent on her ability to have children. This is annoying and also confusing. Women are more than mothers or potential mothers. Motherhood can be part of a woman's life but is not her life.

Women who make clear that they decided not to have children may face hostile reactions. They are sometimes called egoistic, irresponsible toward society or are pitied for missing an essential part of womanhood and therefore for having an incomplete life. They are warned of future regret: "One day it will be too late and then you will be sorry you do not have a child." As if that in itself would be a reason to get pregnant! Or "what if you are old, you will have nobody to visit you." In all sorts of ways, the message that a childless life is incomplete reaches us. Needless to say, voluntarily childless women have no such worries.

Freedom

These almost daily reproaches may be annoying for voluntarily childless women and they are painful for involuntarily childless women. Both would benefit from a change of attitude towards motherhood. Having reproductive organs should not determine how women spend years of their lives. Women should have the psychological and economic freedom to choose for motherhood and to not choose for motherhood. The decision to have a life without children of your own should be respected and regarded as one of the many decisions people make in their lives.

Our Victory in New York

By Amanda Sherman and Cecelia Volk

Up until 1986, New York law allowed personal injury lawsuits only when they were filed within three years of exposure to a toxic substance. DES-exposed individuals whose injuries did not show up until their late teens or early 20's were "time-barred" from filing a lawsuit. To challenge the injustice of that law, a grassroots coalition was formed in 1981. DES Action was part of that group which informed the public, lobbied the state legislature, and in 1986 helped write a new page in legal history.

New law enacted in 1986

On July 30, 1986, the New York State Legislature revised the statute of limitations for injuries relating to five toxic substances: DES, asbestos, tungsten carbide, chlordane and polyvinylchloride.

"To challenge the injustice of that law, a grassroots coalition was formed in 1981."

The statute was extended to include a three year time period from the appearance of symptoms. This landmark law also created a one-year "window of opportunity" in which claims based on old injuries could be filed.

Court of Appeals 1989 ruling

We thought we could finally have our day in court. But first, we had another legal battle to fight with the drug companies, who challenged the constitution-

ality of the new law. On February 15 this year, the New York State Court of Appeals (the state's highest court) heard oral arguments for *Hymowitz v. Eli Lilly, et. al.*, the first DES case filed under the new law. On April 4, less than two months later, the Court gave its decision, which modifies the notable *Bichler v. Lilly Co.* case. By a 5 to 1 ruling, the Court held that the revival window was constitutional and that there was no violation of either due process or equal protection under the law. Furthermore, a companion ruling (aimed at DES litigants only) recognized the liability of all DES drug manufacturers except those able to prove their product was not marketed for pregnancy-related purposes.

Product identification

The Court also recognized the unique aspects of product identification involved in DES cases. Because of the inherent difficulties in identifying a specific manufacturer of DES, the Court ruled that DES daughters were no longer required to prove which company made the DES taken by their mothers. However, the Court made it clear that this ruling applied only to DES cases, and not to the other four substances named in the statute, or to other personal injury cases involving product identification.

Market share liability

Accordingly, the Court's decision offers the broadest legal guidelines for manufacturers' liability issued to date. A key

element in the New York ruling is the assignment of market-share liability, whereby DES drug manufacturers will be required to pay damages based on a portion equal to their share of the DES national market during the year the drug was taken.

While market-share liability eliminates the plaintiff's need to prove product identification, it also means that full recovery of

"...DES daughters were no longer required to prove which company made the DES..."

awarded damages is not guaranteed.

Lessons learned

The efforts of one well-organized, hard-working DES coalition helped pave the way for over 500 DES lawsuits in New York state. To qualify for legal proceedings in New York the "cause of action" must have taken place in the state, meaning that the law applies to DES victims who were either born in New York state, or whose mother purchased or ingested DES while residing in the state. Of course, the legal decision rendered in New York holds true only for suits filed in that state. Other states' "case" law may be different and will not be changed by the recent ruling in New York. Contact an attorney if you are thinking about filing a DES lawsuit. Our San Francisco office can provide legal referrals for some states.

Our Personal Triumphs

By Sue Lawler

As DES exposed, we are often forced to face many negative health risks. We learn to accept these as part of our lives. Yet, we can become focussed or at times even obsessed with our DES-related medical ordeals. Sometimes we need to step back and celebrate our lives despite our DES exposure.

As a DES daughter, I have been forced to become astute about my body and my health care. And as a director of a local DES Action chapter (Pennsylvania) I have learned a great number of skills I never dreamed of. Overcoming the difficulties of sharing personal DES tragedy has led to sharing DES information with several hundred people at one time. There are indeed many things I, as a DES exposed person, can do because of being DES exposed.

Being able to achieve in spite of DES exposure is an accomplishment, and my greatest one is double—their names are Keith and Jill, my children. After enduring multiple miscarriages, and a long period of infertility, Keith Ryan Lawler was born to us on September 19, 1980. A beautiful healthy baby boy who captured all our unspoken hopes. Our DES related fears were relieved.

However, 11 months later my husband Fran, a DES son, was diagnosed as having testicular cancer. Doctor visits, surgeries, fears, we were back in a DES whirlwind. In the next few months Frannie was recovering, Keith was flourishing. Months passed into years, our DES Action chapter grew as quickly

as our son.

I feared another bout with DES reality when I started experiencing abdominal pain and my menstrual cycle stopped. My doctor delivered his diagnosis—pregnancy. I was due to have a baby on or about September 19, 1983. Anyone who did not know our personal medical histories commented about our perfect family planning. Frannie and I, our families, our doctors, were surprised and thrilled. After a difficult 9 months, Jill Robin Lawler was born on September 12, 1983. Our beautiful daughter stole everyone's hearts. I found it hard to believe that I was in part responsible for such wonderful little people. They were often referred to as "miracle babies,"

but I believe each and every baby born is a miracle.

About 80% of DES daughters can have a successful pregnancy. Some couples are infertile due to DES exposure and their babies come to them in a different manner.

I do not want to imply that having a family is everyone's triumph over DES. For me, it is a personal triumph, something I achieved in spite of my exposure. But each one of us who is exposed can search and someday find our own personal triumph. And when we do, we will share the same joy, sense of pride and accomplishment as I do when I kiss my children goodnight and hear "I love you mommy." ☺

letters to the editor

Dear Editor:

I am a DES daughter and am writing to share my experiences with infertility and pregnancy. I have the T-shaped uterus and cervical hood common in DES daughters. During 6 years of infertility workups, it was found that my fallopian tubes "may" not be picking up the egg properly, that the sperm "may" not be getting through the cervical hood, implantation "may" be a problem in the T-shaped uterus, and I also have sperm antibodies. Needless to say, a lot of doctors, tests, uncertainties and heartache.

After trials with artificial insemination and Clomid, our last hope was the GIFT procedure. I was concerned and aware, as are most DES exposed

persons, that this is still certainly experimental in nature and the long-term effects are unknown.

October of 1987 we became pregnant through the GIFT procedure only to miscarry in December, a week before Christmas. We were devastated. We had been through so much emotionally and physically that we said, never again. Our specialist then made a break-through in the GIFT procedure which increased the pregnancy rate and lowered the miscarriage rate. He encouraged us to try again. We did so in June of 1988. We became pregnant again, this time successfully. Of course, we knew that DES daughters have a high risk for cervical incompetence. Therefore I was examined on a weekly

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Back Issue Order Form

Many of our readers have joined after some of these issues were printed. For your convenience we list the contents for the last 8 years.

Volume 3 1981-82

- ☐ No. 1 Maternity care for DES daughters; Book Review: *DES Daughter* by Joyce Bichler; Warning on cryosurgery; Upper genital tract changes and pregnancy outcome.
- ☐ No. 2 Reproductive problems in DES daughters; Ultrasound to rule out ectopic pregnancy; Testicular cancer and testicular self-exams.
- ☐ No. 3 Book Review: *When Pregnancy Fails*; Information for DES sons; Some DES daughters have withered tubes; Cancer in pregnancy.
- ☐ No. 4 Editorial: Putting DES exposure in perspective; Tace and DES daughters; Reproductive experience in DES daughters.

Volume 4 1982-83

- ☐ No. 1 DES and the Military; The psychological impact of problems with pregnancy.
- ☐ No. 2 Endometriosis: Personal View; From DES daughter to preemie parent;
- ☐ No. 3 DES Action Netherlands; Ectopic pregnancy—two reports; Update DES and food.
- ☐ No. 4 New developments in sex hormone abuse; Pelvic inflammatory disease and DES daughters; Vaginal infections: caring for yourself.

Volume 5 1983-84

- ☐ No. 1 Cancer in DES sons; Transition of adenosis to clear-cell carcinoma; Book Review: *Getting Pregnant in the '80s*.
- ☐ No. 2 DES Cancer Network forms; Psychological impact of DES exposure; Impact of infertility; Book Review: *DES The Bitter Pill*.
- ☐ No. 3 Progesterone exposure in pregnancy; The misunderstood loss: miscarriage; Effects of DES on oviducts and ovaries of mice.
- ☐ No. 4 Bill to aid DES-exposed introduced in Congress; Recommendations to government for action on DES; Current DES uses.

1984-85

- ☐ Issue No. 21 Summer 1984
Deciding about fertility treatments; Personal view; I owe my life to an article; Pregnancy questions, progesterone during pregnancy.
- ☐ Issue No. 22 Fall 1984
Editorial: Limits on lawsuits; Health history questionnaire; Book Review: *Modern Meat*.
- ☐ Issue No. 23 Winter 1985
Dysplasia in daughters, breast cancer in mothers; DES Cancer Network; Book Review: *To Do No Harm*; Testicular cancer network.
- ☐ Issue No. 24 Spring 1985
Federal DES Task Force Meeting; Dysplasia: treatment options; Endometriosis.

1985-86

- ☐ Issue No. 25 Summer 1985
Birth Experiences: 2 DES sisters; Book Review: *Menopause, Naturally*; Dear Doctor: T-Shaped Uterus.
- ☐ Issue No. 26 Fall 1985
DES Action Hosts Second Research Conference; Endometriosis; Legal News.
- ☐ Issue No. 27 Winter 1986
Health histories of the DES-exposed; Warning on menopausal estrogen; Film Reviews: *The Ultimate Test Animal* (Depo-provera) and *DES: Uncertain Legacy*.
- ☐ Issue No. 28 Spring 1986
The New Reproductive Technologies; Dear doctor: Treatments for dysplasia and carcinoma in situ.

1986-87

- ☐ Issue No. 29 Summer 1986
NCI requests studies on breast cancer; PMS backlash; DES sons.

- ☐ Issue No. 30 Fall 1986
Victory in NY law; Ovulation pump; Premature labor; Estrogen and osteoporosis.
- ☐ Issue No. 31 Winter 1987
Bovine Growth Hormone; Medical Abstracts; Upper uterine changes; Para-ovarian cysts; Reproductive technology; Cerclage; Breast screening program.
- ☐ Issue No. 32 Spring 1987
DESAD Study Report; New breast self-examination method.

1987-88

- ☐ Issue No. 33 Summer 1987
Clomid; "Host" Uterus; Fallopian tube problems; pregnancy stories.
- ☐ Issue No. 34 Fall 1987
Infertility and ectopic pregnancy; Book Review: *The Medical Self-Care Book of Women's Health*; Letters: success story; Clomid.
- ☐ Issue No. 35 Winter 1988
Estrogen replacement; Research conference.
- ☐ Issue No. 36 Spring 1988
High-risk pregnancy; Pregnancy books; Ectopic pregnancy.

1988-89

- ☐ Issue No. 37 Summer 1988
10 years of DES Action; Medical updates; immune deficiencies; daughters' infertility.
- ☐ Issue No. 38 Fall 1988
Basic care for mothers, daughters, sons; Pap test; Cervicography.
- ☐ Issue No. 39 Winter 1989
Infertility: When is Enough Enough; DES Action and patient care.
- ☐ Issue No. 40, Spring 1989.
Birth control Update, DESAD report; confidentiality, endometriosis.

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LETTERS *continued from page 6...*
basis early on and had periodic ultrasounds to check the cervix. My cervix held up just fine and the good news is that we gave birth to a healthy, beautiful baby girl in February 1989, only one week early!

I hope this is of some encouragement to DES daughters who are presently going through a similar situation.

Deanna Popielarz

Dear Editor:

I am writing this letter out of my own sorrow and hope it will serve as a warning and guide to others. I lost my second pregnancy at 21 weeks last September. Here are a few 'signs' to be aware of when choosing a doctor:

- If you have trouble becom-

ing pregnant, by all means see an infertility specialist. Then leave that doctor when you become pregnant. "Infertility" does not mean 'high-risk' pregnancy care. A good infertility doctor just deals with infertility. And a good high-risk doctor will only deal with maintaining the pregnancy.

A good high-risk doctor will be someone who:

- only takes high-risk patients, no "normals"
- can tell you exactly how many DES women she/he has seen and what the outcomes were, and why
- has a reputation for vigilance, maintenance, and, importantly, aggressiveness.
- is sensitive to your emotional needs and is not threatened by questions or demands.

I might add that a good doctor will have more than two procedures for a given situation and does not have a "wait and see" mentality regarding your pregnancy. A good doctor will give you realistic, not hope-a-mistic—chances for a successful pregnancy.

Do not make the mistake of going to a "nice" doctor if that doctor has no real hands-on experience with your specific problem (example: incompetent cervix and T-shaped uterus). Do not listen to any doctor who tells you there are easy solutions to DES-related pregnancy loss.

I say all these things because what they add up to is the difference between having or not having a child.

L.S., Los Angeles

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