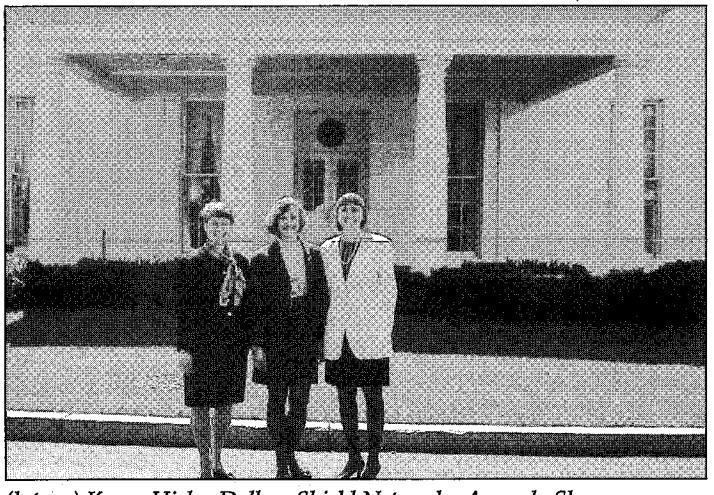
THE DES ACTION
VOICE
A FOCUS ON DIETHYLSTILBESTROL
Spring 1996 #68

DES Action Stands Firm Against Liability "Reform"

Twenty years ago a group of pioneering DES mothers and daughters sat around a small kitchen table to express their frustration about the government's lack of action to inform the public about the dangers of DES. Today, after taking matters into our own hands, we're sitting at a table of another kind—located in the Cabinet room at the White House—to help shape national policy at the highest levels.

Once again, debate in the halls of Congress is centering on legislation which will provide a green light for corporate misconduct by making it virtually impossible for those harmed by dangerous products to receive full compensation for their injuries.

Recently, the House of Representatives approved final passage of the mis-named "Common Sense Product Liability Legal Reform Act" (also known as tort "reform") as part of the "Contract with America." Unfortunately, the only relation this legislation has to common sense is that it's easy to see that if this bill becomes law, it will drastically curtail the ability of consumers to bring irresponsible manufacturers to justice.



(l. to r.) Karen Hicks, Dalkon Shield Network, Amanda Sherman, President, DES Action, Karen Renick, Board Member, DES Action.

DES Action has actively opposed product liability "reform" since 1980 on the grounds that it is designed to protect big business at the expense of U.S. consumers. Over the years, hundreds of you have sent moving personal letters to Capitol Hill to help turn the tide against unbalanced tort "reform" legislation (see The DES Action **Voice**, #61, Summer 1994).

Your stories continue to be a poignant reminder that innocent people are at the real center of this debate.

Last March, shortly after President Clinton announced plans to veto this anti-consumer legislation, DES Action was invited to the White House to bring our side of the story to the product liability debate. On March 26, representatives from DES Action met with President Clinton's Chief of staff, Leon Panetta, in the Executive Offices. In summarizing DES Action's position against tort "reform," board members Amanda Sherman and Karen Renick spoke on behalf of all DES mothers, daughters and sons. Here is what they said:

- That punitive damages, although seldom awarded, are an important deterrent for corporations not to place profit over people by manufacturing poorly tested products like DES. They also explained that if efforts to restrict punitive damage awards are successful, then attorneys will be less likely to take DES cases in the future.
- They spoke about the need to be fully compensated for "non-economic damages"—such as the loss of fertility, or the death of a

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Mothers—Tell Us Your Story

We are looking for DES mothers willing to share the circumstances surrounding their having taken the drug. DES Action feels this is a very important part of our history and wishes to document it. Please tell us where you received the drug, why it was prescribed, how long you took it, and the manufacturer and amount taken if known. You may include any other information you like, i.e., how long during the pregnancy it was taken, number of pregnancies and year each occurred, etc.

Your letter will be confidential and if you wish to remain anonymous, you may. Include your current age and state where you reside. Mail the information to our Oakland address (below).

Notice to Daughters

In preparation for an article we plan to write, we would like to know the age at which you first learned of the problem, a short description of your particular infertility problem, any treatment you required, and the outcome. If you have friends or siblings or children who also experienced DES-related infertility, please ask them to participate as well. Mail the information to our Oakland office. Your response need not be long; even a postcard will do. Your confidentiality will be respected, and you do not need to identify yourself by name if you wish to remain anonymous.

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Truth-telling on Breast Cancer

by Theresa Lemieux, DES Action Canada Newsletter, Winter 1996.

Breast cancer activist and renowned surgeon Dr. Susan Love appeared something more like a visionary to the women who came to hear her speak at Concordia University in Montreal on January 29. Dedicated to "truth-telling" as she calls it, Dr. Love claims that her most important function is to clear up garbled information and provide a clear context for understanding what we know about breast cancer. But her work doesn't stop there.

On top of her attack on popular myths about breast cancer, Dr. Love makes some assertions that indicate growing support for studies that investigate the link between estrogen exposure and breast cancer. She refutes the claim that estrogen exposure is safe, citing various small and inconclusive studies as the resource for this popular misinformation. In the U.S., some modest studies done on the benefits of estrogen therapy for heart disease patients have shown marginal improvement for the studies' subjects. From this information, Dr. Love says, was extrapolated the claim that estrogen is good for you. While she questions several assumptions behind the conclusions, she maintains that they do not prove anything about the safety of prescribing estrogen, much less its supposed health benefits. Rather, it seems that healthy women, both in studies and in the general public, are being given estrogen without proper clinical assessment of the results.

Dr. Love is worried by the popular acceptance of the very drugs she thinks should be used with extreme caution. Doctors can create a false understanding of the effectiveness of estrogen replacement therapy by the information they fail to offer their patients. For example, Dr. Love says many doctors often neglect to tell women who are taking Premarin (an estrogenic drug prescribed to relieve the symptoms of menopause) that in order to quit, they must be weaned from the drug. Just as the body gradually declines in its production of estrogen, a high-dose presciption should taper off, rather than force the body into instant withdrawal.

"...she maintains that [these studies] do not prove anything about the safety of prescribing estrogen, much less its supposed health benefits.."

"They tell you to take it, and when you stop, your body gets a shock and you feel bad. Take it again and you feel better—so it MUST be good for you," she reasons mockingly. Such defective logic is just the kind of interpretive flaw that oversimplifies the effects of any medication on the body.

Dr. Love has little faith in a quick-fix approach to medication. She derides paternalist attitudes among those of her peers who attempt to turn natural processes such as menopause into chemically treatable diseases by creating jargon labels like "estrogen deficiency disease." "Remember that this is big business," she warns, "and that Premarin is the number one marketed drug in the U.S. today." She herself is nervous about prescribing estrogen to women with breast cancer, she says, since there are no studies to support the claim that it is a reasonable and safe medical practice.

Dr. Love will pioneeer the growing interest in estrogen research in her next book (currently in progress). Since only 5% of breast cancer is caused by genetics alone, Dr. Love plans to tackle environmental factors as the main "culprit" behind breast cancer, and the next growing area for research.

Dr. Love also mentioned the omnipresence of pollutants such as DDT in our environment. Although its usage is banned in North America, it is still used in many countries from whom we buy fruit and vegetables. DDT and other pesticides are metabolized by the human body as estrogens, the effects of which we are just beginning to study, Love says. We do know that exposure to radiation increases our vulnerability to environmental estrogens, but the discovery of the full range of effects from synthetic hormones belongs to the future.

As part of her ongoing crusade against the "slash, burn and poison" approach to treatment, she stresses that she will continue

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CANCER *from page 3...*
to fight for research dollars directed towards prevention. As she sees it, prevention and political action are our future.

Dr. Love encourages women to "be obnoxious" and to demand funding to find something better than the methods of detection and treatment available now. Being informed makes us better advocates, she reminds us, as she urges women to educate themselves further. "We've seen the defeat of many cancers in my lifetime, and there's no reson why breast cancer can't be defeated too!"

DES Action Canada has just published a new booklet, A New Look at Breast Cancer—Beyond Early Detection. You can get an international money order at your post office for $5 and send to them at: 5890 Monkland, Suite 203, Montreal, Que H4A 1G2, Canada (postage to Canada is 46¢).

Our Stolen Fut

Theo Colborn, Dianne Dumanoski, and John Peterson Myers, *Our Stolen Future: Are We Threatening Our Fertility, Intelligence, and Survival?—A Scientific Detective Story.* Published by Dutton/Penguin. $24.95

We always knew we were only part of a bigger picture, the "canaries in the mine" that show up dangers. There is poignancy to the title of this study, because that is what many of us have found out. Options have been closed: we cannot bear children, and many DES-exposed have ongoing health problems that can influence their working lives.

Principal author Theo Colborn has collected research on man-made chemicals and their effects on animals and humans, to uncover a disturbing pattern. Life on our planet is being changed and challenged by thousands of chemicals in our environment. No one thought that some of these compounds, such as those used as pesticides, would leach into the water supply and affect the fertility and body formation of fish, the birds that feed on them, and ultimately those at the top of the food chain–us.

In the past, government health agencies have looked at chemicals from the perspective of cancer risk. They have not studied a slower-emerging danger, that of hazards to reproduction. The authors write:

"Hormone-disrupting chemicals are not classical poisons or typical carcinogens. They play by different rules. They defy the linear logic of current testing protocols built on the assumption that higher doses do more damage. For this reason, contrary to our long-held assumptions,

TORT *from page 1...*
baby. These tragedies, as you known, are the most devastating type of loss a person can experience. Yet, this legislation seriously devalues "noneconomic" damages, while protecting the "economic" loss of a corporate paycheck.

They pointed out how this bill will disproportionately harm women—for it is women who, historically, have been at greatest risk from dangerous products like DES, the Dalkon Shield, and silicon-gel breast implants. By capping punitive damages for reproductive injuries, this bill increases the vulnerability of women to dangerous products. And by treating economic and non-economic damages differently, this bill creates a two-tiered legal system which hurts women and children in particular, whose injuries are not typically related to lost wages.

Mr. Panetta and his staff listened carefully. And last week, DES Action was invited to return to the White House—this time to explain the full history of DES to other consumer groups and policy makers.

Once again, we made it clear that product liability lawsuits aren't the cause for the litigation crisis in this country, when only 1 in 10 people who have been injured by defective products ever goes to court. Nor are lawsuits about greedy lawyers. Rather, they're about people like us, whose lives have been dramatically—and in many cases irreparably—harmed by dangerous products like DES. To lose sight of this is to engage in a grave disservice for all of us who were exposed to DES.

If the free market were infallible, DES would never have been sold. If the government were all-knowing, DES would never have received FDA approval. When public pressure and government action fail to keep the marketplace safe, the courts are our last forum of resort.

Amanda Sherman is President, and Karen Renick is a board member, of DES Action.

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screening chemicals for cancer risk has not always protected us from other kinds of harm. Some hormonally active chemicals appear to pose little if any risk of cancer...such chemicals are typically not poisons in the normal sense. Until we recognize this, we will be looking in the wrong places, asking the wrong questions, and talking at cross purposes....

"At levels typically found in the environment, hormone-disrupting chemicals do not kill cells nor do they attack DNA. Their target is hormones, the chemical messengers that move about constantly within the body's communications network. Hormonally active synthetic chemicals are thugs on the biological information highway that sabotage vital communication. They mug the messengers or impersonate them. They jam signals. They scramble messages. They sow disinformation. They wreak all manner of havoc. Because hormone messages orchestrate many critical aspects of development, from sexual differentiation to brain organization, hormone-disrupting chemicals pose a particular hazard before birth and early in life.... The process that unfolds in the womb and creates a normal, healthy baby depends on getting the right hormone message to the fetus at the right time."

Dr. Colborn first brought this message to the scientific community in a conference she organized in 1991. A consensus statement from this meeting included the following:

"A reevaluation of the in utero DES-exposed population is required for a number of reasons. First, because the unregulated, large-volume releases of synthetic chemicals coincide with the use of DES, the results of the original DES studies may have been confounded by widespread exposure to other synthetic endocrine disrupters. Second, exposure to a hormone during fetal life may elevate responsiveness to the hormone during later life. As a result, the first wave of individuals exposed to DES in utero is just reaching the age where various cancers (vaginal,, breast and prostatic) may start appearing if the individuals are at a greater risk because of perinatal exposure to estrogen-like compounds. A threshold for DES adverse effects is needed. Even the lowest recorded dose has given rise to vaginal adenocarcinoma. DES exposure of fetal humans may provide the most-severe-effect model in the investigation of the less potent effects from environmental estrogens. Thus, the biological endpoints determined in in utero exposed offspring will lead the investigation in humans following possible ambient exposures."

Twenty years earlier, in the landmark report in the New England Journal of Medicine on the association between DES and clear-cell cancer, the Journal with unusual foresight described that article as "of great scientific importance and serious social implications..." Dr. Colborn and her co-authors are showing us that importance and those implications.

Our Stolen Future has a chapter on "Defending Ourselves" that has practical ideas for all of us, DES-exposed or not.

To summarize:

- Know your water and urge at least monthly testing, especially for pesticides.
- Children and women of childbearing years should avoid fish contaminated with dioxin, PCBs and DDE.
- Avoid animal fat as much as possible. Meats and cheeses are a major source of dioxin exposure.
- Buy or raise organically grown fruits and vegetables.
- Minimize contact between plastic and food and use glass or porcelain for micro-wave cooking.
- Wash hands frequently.
- Never assume a pesticide or insecticide is safe on household pets.

In the public sphere of our lives:

- Shift the burden of proof to chemical manufacturers. The current system "assumes that chemicals are innocent until proven guilty. This is wrong. The burden of proof should work the opposite way..."
- Set standards–now based on a 150-lb. adult male–that protect the most vulnerable, children and the unborn.
- Require producers to monitor their products for contamination.
- Support a comprehensive research effort, and redesign of the manufacture and use of chemicals.

This book's "scientific detective story" has followed the clues and leads us to the culprits. It is up to us to carry out the judgment for humans and defend ourselves.

letters to the editor

Dear Editor:

I want to bring up a medical issue that may be DES related. I have recently been diagnosed as having osteoporosis. While this is disturbing in and of itself, at the age of 44, it is even more so.

Current research seems to indicate that progesterone plays a big part in building bone. This is especially critical during early development (teenage years), where optimum bone mass is being built. One's densest bone mass is attained by age 20. Given the fact that I was DES exposed; that my periods were incredibly erratic during my teenage years (45-60 day cycles); and that I seemed to have a luteal phase defect during my 30's (24 day cycles, very short luteal phase); it would appear that I did not produce much progesterone during much of my lifetime. My doctor hypothesizes that my condition is not a recent phenomenon, but that I started out with low bone mass. The question necessarily follows whether this is yet another result of being DES exposed.

I would like to know if any scientific research from this angle has been done on DES-exposed daughters. It continues to amaze me that every phase of my life seems to have been affected by this exposure. And every time you think you can put it aside for awhile, it comes back again in a different guise.

D.T.
New Haven, CT.

Dear Editor:

I am a 39-year old DES daughter who has suffered for over 17 years from a painful eye condition called recurrent corneal erosion. The opthamologists who have examined my eyes have noted the unusual and atypical cellular structures in my corneas. When I questioned one physician as to whether the erosions could be a result of my DES exposure, he said that it was possible, but difficult to prove. Have any other DES exposed people reported recurrent corneal erosions?

Debra Carney
Massachusetts

Dear Editor:

I am a DES daughter with a moderate T-shaped uterus. My first pregnancy was last year. At 22 weeks my cervix began to thin and I was put on total bed rest. After 6 days I experienced a premature rupture of membranes. I was taken to the antenatal unit of a hospital. Seven days later, at 24 weeks, my son was born. He weighed 710 grams. He was not considered a candidate for resuscitation and only lived for two hours.

I would like to speak with other women who have had the same experiences and have had a second pregnancy. I am considering a second pregnancy but want more information on what the possible outcomes are. Also I would like to speak to women who have had pregnancies after having hysterscopic metroplasty surgery. They may write to me at 2610 Yuma Drive, Chino Valley, AZ 86323 or they may call me collect at 520-636-9566.

Marie Wise
Chino Valley, AZ

book note

As the authors write, "Imagine leaving your doctor's office just having been diagnosed with a disease that you don't understand; you know nothing about it; you can't even pronounce its name! You feel frustrated, confused, and scared. And most of all, you feel alone. Unfortunately, this is the case for many women diagnosed with endometriosis. They don't know where to turn for comfort or support, much less definitive information."

Here at DES Action, we often have phone calls from DES-exposed women with endometriosis. They want to know if DES is responsible, and what they can do about this condition. The Endometriosis Association has been working since 1980 to provide support and education, and has just published The Endometriosis Sourcebook. The book is available from them at 8585 North 76th Place, Milwaukee WI 53223, at $14.95 plus $2.75 shipping costs. They also have a regular newsletter and referrals to support groups in many parts of the U.S.

Renew Now & Save!

Effective June 1, membership fee increases from the present sliding scale of $30-60 to $35-70 because of postage, printing and telephone costs. The low-income fee of $10 remains. You can tell when your membership lapses by the number in the upper right corner of your mailing label: this is issue 68, Summer 1996 is 69, and so on.

Fertility Treatments for Daughters

Krumholz et al, *"Problems of a DES-Exposed Woman in her Child-Bearing Years," J. of Clinical Outcomes Management, Obstetrics and Gynecology Edition,* November 1995.

This is a lengthy overview, written by a number of experts, on the risks that a DES daughter faces when she wants to have a child. We believe that our readers will be interested in the response of Steven Brenner M.D., (Chief, Reproductive Endocrinology, LIJ Medical Center, New Hyde Park NY) to the question, "Is the treatment of infertility altered by prior DES exposure?"

"Given the specific problems a DES-exposed woman can develop, the infertility workup and treatment of such women should be aggressive and not delayed. For example, because specific HSG findings could predict greater difficulty conceiving, an HSG study should not be withheld until after one year of unsuccessful attempts to conceive. Similarly, the DES-exposed woman who has a "pinpoint" os or has undergone cervical surgery should be considered at high risk for cervical factor infertility and, thus, evaluated at the outset of her pregnancy attempts...

"Treatment for unexplained infertility in the DES-exposed group will include superovulation and intrauterine insemination. Unfortunately, expectations for success are compromised in the infertile DES-exposed woman, and such patients may require the use of assisted reproductive technologies (that) involve superovulation, oocyte retrieval, embryo transfer, and—with gamete intrafallopian tube transfer (GIFT)—placement of oocytes and sperm into the fallopian tubes...

"DES exposure could be considered a relative contraindication to GIFT, because ectopic pregnancy is more common in DES-exposed women, even without gross total abnormalities. Ectopic pregnancy is a risk associated with IVF, despite the fact that embryos are placed directly into the uterus. Embryos do not implant immediately and may float into the tubes in a retrograde manner. Proper tubal function is needed to advance the embryos back into the uterine cavity. Karande et al reported 3 ectopic pregnancies of 19 clinical pregnancies (16%) in DES-exposed patients as compared to 18 ectopic pregnancies of 373 pregnancies (5%) in control patients without DES exposure but with confirmed tubal disease. DES may increase the risk of ectopic pregnancy in IVF.

"The implantation rate per embryo transferred in DES-exposed women has been shown to be significantly less than in controls (7% verses 11.2%). The ongoing pregnancy rate was found to be significantly lower and the miscarriage rates higher in DES-exposed women. The outcome of IVF showed a trend toward a worse prognosis in patients with constrictions and a combination of T-shaped uterine abnormalities and constrictions on HSG..."

Burton Krumholz, M.D. director of the DES Screening Clinic at LIJ Medical Center, added that "the need for assisted reproductive technologies is a very real possibility for DES-exposed women...Careful counseling with regard to the risks of repeated ectopic pregnancies is essential. The relative contraindication to GIFT must be explained..." Dr. Krumholz made an interesting comment on another procedure:

"Although little has been written on the subject, successful use of a vaginal pessary to hold the cervix up and change its axis was shown in a comparison of bed rest, cervical cerclage, and vaginal pessary for management of cervical incompetence in a large unpublished series involving DES-exposed pregnant women (personal communication with Dr. Stephen Wilson, July 1995)...

We conclude these excerpts with another statement from Dr. Krumholz that brings out the human, not just the biological, side of this topic:

"The problems relating to cervical incompetence and preterm labor are emotionally charged and economically harrowing and involve difficult decisions for the patient, her partner, and her family. Already regarding themselves as victims of inappropriate exposure to a damaging medication (DES), these women find it extraordinarily difficult to elect to undergo treatment with agents such as clomiphene citrate and menotropins, although they themselves do not yet have an in utero passenger. The thought of taking various tocolytic agents while pregnant and exposing one's baby to a transplacental dose of these medications carries an enormous emotional impact, despite physician reassurance of the safety of these therapies."

Notes from Nora

On March 26, Pat Cody and I traveled to Houston, Texas for a meeting of the National DES Education Program Steering Committee. We heard reports from the five regional centers about their progress in conducting their pilot DES educational projects.

Most of the centers have completed their outreach and will soon begin gathering data about the effectiveness of their efforts to educate selected communities about DES. By comparing random community surveys taken before and after their outreach efforts, we will be able to see whether knowledge and awareness of DES and its effects has increased.

At DES Action we are eager to learn which outreach techniques worked best, and what members of the public retain regarding the effects of DES. We will apply the best methods to our own work.

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On March 30th our Board of Directors held their spring meeting in San Francisco. Here are some of the highlights of the meeting.

Symposium Planned
The Board approved a proposal to seek financing for a Symposium on the topics of menopause and reproductive technologies (also known as fertility treatments), the two most popular areas of inquiry from our members. The tentative site is Boston, and the tentative date is the fall of 1997.

Future of National DES Education Program
Board members are investigating ways to fund an expansion of the so-called "National DES Education Program" currently sponsored by the National Cancer Institute. This program, which DES Action brought into being through our drive for DES research and education, is actually composed of small pilot projects. Our goal is a truly national program which can reach all areas of the country and all DES-exposed individuals. ❦

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