V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Summer 1997

#73

DES taken off the market by Eli Lilly!

li Lilly & Company, major manufacturer and marketer of the notorious cancer-causing drug DES (diethylstilbestrol) has decided to discontinue selling DES. We recently learned this after hearing several reports that men seeking DES for treatment of their prostate cancer were being turned away at pharmacies. (In recent years DES has been used primarily to treat prostate cancer.) We called Eli Lilly to find out what was happening.

This is what they told us: "It is true. Eli Lilly has discontinued DES and we have exhausted current supplies." I asked why and was told that "the company that supplies us with the raw materials for DES has stopped production."

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We think the DES-exposed community can take credit for finally getting this drug off the market.

Citing "proprietary information" reasons, the Lilly representative would not tell us why the company had stopped production. It occurs to us that a company with the resources of Eli Lilly could find a way to obtain the raw materials for DES if they wanted to. At its heyday in the 1950s and early 1960s DES was made by over 200 different drug companies. It is thought to be fairly simple to manufacture.

More likely, Lilly has decided that continued manufacture of DES is more trouble than it's worth. We believe that Lilly's decision has come about as a result of the increased clout of DES-exposed consumers, as evidenced by

new legislation introduced in Congress this year. Given the higher profile we've achieved from our efforts in Congress, Judy Helfand's film *A Healthy Baby Girl*, and other activities, we think the DES-exposed community can take credit for finally getting this drug off the market. Only 59 years too late.

As they launch major new drugs for osteoporosis treatment and estrogen replacement, Lilly is also trying to promote itself as a company women can trust and has recently sponsored several high-profile women's health events. Their continued manufacture of DES may have been seen as an unpleasant reminder of a public health fiasco and at odds with these public relations efforts.

DES Action is pleased that Lilly has finally seen fit to stop producing DES. We continue to call for Eli Lilly to acknowledge that DES causes cancer and serious reproductive health problems, and to apologize to the millions of Americans harmed by their product.

E DES ACTIO

DES Action Affiliates

Each group was created and nurtured by volunteers. Write them if you want information on their activities or can volunteer.

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DES Action New Zealand Prof. Charlotte Paul Preventive and Social Medicine Otago Medical School Box 913 Dunedin, New Zealand ES (diethylstilbestrol) is a synthetic form of the female hormone estrogen. From 1938 to 1971, several million pregnant women in the U.S. were prescribed DES, especially if they had a history of previous miscarriage or slight bleeding or had diabetes. DES was given in pills, injections and suppositories and sold by over 200 drug companies under their own brand names.

DES exposure can lead to health problems:

- DES mothers have an increased risk for breast cancer
- DES daughters have a 1 in 1,000 risk for a rare vaginal/cervical cancer, clear-cell adenocarcinoma. This is the reason all daughters need regular gyn exams. They also are at risk for reproductive difficulties: infertility, ectopic pregnancy, miscarriage and premature delivery, and should always receive high-risk pregnancy care.
- DES sons have an increased risk for undescended testicles, cysts on the epididymus, and possibly for infertility.

DES Action, the major consumer group working on this issue since 1974, has special publications, physician referral lists, attorney referral lists, this quarterly newsletter, and a hot-line:

1-800-DES-9288.

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Members are Invited to Attend! Call today to reserve your place at The DES Action 1997 Symposium:

Dills and Potions:

Reproductive Technologies, Menopause, and Our Future

Saturday, October 18, 1997 Ramada Rolling Green Hotel & Conference Center Andover, MA

Featured speakers:

(morning program)

- Janine O'Leary Cobb Editor, A Friend Indeed menopause newsletter
- Dianne Dumanoski Co-author, Our Stolen Future
- Burton Krumholz, M.D.
 Director, DES Screening Center, NY
- Judith Turiel, Ed.D.
 Co-author, Preventing Preterm Birth and forthcoming book about new reproductive technologies

Afternoon Workshops:

(choose two)

- Adoption
- Preparing for menopause: nutrition and exercise
- Infertility & reproductive technologies
- General medical questions about DES
- **DES Sons:** The need to know

Prior registration required
For more information or to register:
DES Action USA

1-800-DES-9288

VOICE

Notes from Nora

e have exciting news and plans to announce. Please note (p. 3) that you are invited to attend our 1997 DES Symposium in Andover, MA, on October 18. Prior registration is required, and we urge you to call today if you are interested.

Our really big news is that on June 4th "The DES Education and Research Amendments of 1997" was introduced into Congress by Representative Louise Slaughter and Senator Tom Harkin. The bill—H.R.1788 in the House; S.834 in the Senate—will provide for a continuation of funds for DES research and for the establishment of a National DES Education Program under the direction of the Secretary of Health and Human Services.

The DES bill is essential for every DES-exposed person in this country. Why? Because each of us needs to know the long-term consequences resulting from DES exposure. This is the research that is tackling such questions as immune system effects, and possible harm to the third generation—the children of DES daughters and sons. It is only through government-supported research that we will learn the answers to these and other urgent questions.

In addition, the DES bill will build upon the small educational pilot projects to reach a larger audience with information about DES. H.R.1788/S.834 would establish a national DES education program for the very first time in history.

We are so grateful to our good

friends Representative Slaughter and Senator Harkin, who again have championed our cause. They successfully sponsored our 1992 legislation and have continued to demonstrate their commitment to the DES community with this year's actions.

We Need Your Help!!

Introducing our bill is just the first step, of course. Now we must garner support from as many legislators as possible, and then carry the bill through the second phase which is appropriations, i.e. getting money to carry out the program. At this point we are asking lawmakers to sign on as sponsors of the bill, and/or to vote for the bill when it comes to the floor.

The only reason the DES bill exists today is because our community has been organized and vocal. Lawmakers—many of them new to the DES issue—must hear from you NOW. They need to hear why the DES bill is so important to you personally. They need to know that their constituents are watching their vote on this piece of legislation.

How to contact your representative and Senators

Each of us has one representative in the House of Representatives and two Senators. Most of us know our Senators, but many may not know your Representative. Here's how to find out who your representative and Senators are, and to contact them:

If you don't know your **Representative's** name and or telephone number, you can call the **Capitol Switchboard at (202)**

224-3121. Simply give the switch-board operator your home zip code and they will be able to tell you who your Representative is and connect you to his or her office. You can call the same number to contact your Senators.

When you reach the offices of the Senators or the Representative, ask to speak with the **Health Aide** and explain the following:

"I am calling from DES Action, the national organization for people exposed to the drug DES. There is a bill in Congress, H.R. 1788, that will help DES-exposed people in (your state or district). I want to ask Senator/Representative _______ to sign on as a sponsor of H.R. 1788. His (or her) many DES-exposed constituents need his/her support on this important legislation."

Feel free to add whatever you wish from your own story, or about the DES issue. If they would like more information, you can refer them to the DES Action national office or to Cindy Pellegrini, aide to Representative Louise Slaughter.

We also welcome letters to your members of Congress.

To write to a Senator: The Honorable (full name) United States Senate Washington, D.C. 20510

To write to a Representative: The Honorable (full name) United States House of Representatives Washington, D.C. 20515

Lastly, you can also send an e-mail message to your Representative and Senators. There is one Congressional web site that lists all e-mail addresses for members of Congress. The web site can be

*** medical report

Recent HRT Reports

lmost daily we receive questions about the safety of hormone replacement treatment (HRT) for DES-exposed women. No studies have been reported on what effects HRT has on DES daughters. Since most DES daughters are just approaching menopause, if studies were done, by the time we found out, the information would come too late to be of use.

There are, however, studies on HRT among post menopausal women. We do not know if these studies included DES-exposed women. Two reports appeared recently.

Beresford et al, "Risk of endometrial cancer in relation to use of oestrogen combined with cyclic progestagen therapy in "Our data suggests that long-term (five years or more) use of combined therapy...is associated with an increased risk of endometrial cancer."

postmenopausal women," *The Lancet*, 15 Feb 1997.

This was a study of women in Washington state aged 45-74 years and included 1,154 women who had developed endometrial cancer between 1985-1991, and a control group of 1,114 women of

those ages who did not have cancer. The conclusion of the researchers: "Our data suggests that long-term (5 years or more) use of combined therapy, even when the progestagen is added for more than 10 days per month, is associated with an increased risk of endometrial cancer."

Grodstein et al, "Postmenopausal hormone therapy and mortality, *The N.E. Journal of Medicine*, 19 June 1997.

These researchers studied data from the long term Nurses' Health Study on the deaths of 3,637 study participants. Their conclusion:

"However, our study population ranged in age from 30 to 73, with similar numbers of deaths

continued on page 8

NOTES *from page 4...* found at **www.capweb.net.**

Thank you for helping to promote H.R.1788/S.834, our new bill. If you need any more information or help contacting your members of Congress, please call me at 1-800-DES-9288.

E E E

The risks for breast, uterine and ovarian cancer for DES daughters in and past menopause, are going to be studied in the first large-scale research on DES to take place in the Netherlands (and in Europe). Dr. Floor E. van Leeuwen, head of the epidemiology dept. of the Dutch Cancer Institute, is being financed by the Prof. Muntendam

Award from the Dutch Cancer Foundation given to Dr. van Leeuwen. We can add to this announcement by stating that this will be the first study anywhere of possible risks DES daughters may face in their menopausal years.

& A A

The risks to female fertility from work-related exposures have been described in the February issue of the *Journal of Occupational and Environmental Medicine*. Researchers studied 281 women with infertility compared with 216 fertile women. They found an increased risk of infertility among women exposed to volatile organic solvents, chemi-

cal dusts, pesticides, and video display terminals. They do not refer to DES exposure; we report this article to our readers as describing factors that may be affecting their fertility.

Many of our readers—mothers of sons, and sons—have had a long wait but at last we have the booklet for DES sons, part of the series we worked on with the National Cancer Institute and several academic institutions. If you would like a copy please send us a 55¢ stamp and we'll get it out to you.

Personal Story

hile my story is not unique to DES daughters across the country, my experiences raise many questions—regarding issues of the quality of life (that is, how far is too far, and am I jeopardizing my future health or that of my unborn child by taking fertility or suppression meds), and issues of self-worth as women and men faced with the choices that infertility and DES exposure present us. How well do providers-who are often more research-oriented or numbersoriented—meet client grief and counseling needs? These were the questions we had to answer for ourselves.

I met my husband thirteen years after learning of my exposure and two years after surgery to remove bilateral ovarian cysts—common in severe endometriosis—with a disturbing prognosis for ever being able to get pregnant. Yet, I was one of the lucky ones—blessed to find a life partner who wanted me because he loved me, not for my

babymaking capacity.

We tried the IVF route once and only once. I remember a dear friend, a certified nurse midwife, telling me that I should never do anything in this quest for a baby that made me feel uncomfortable. For me that meant that our child would either be from both of usor neither of us. We felt that one "college try" was well worth it since we lived in a community with some of the best medical care (University of Utah), reproductive endocrinologists, gynecologists, and geneticists in the country and because there still was a great

from a Utah Daughter unknown as to whether or not I could successfully conceive or bring a baby to term.

It took an additional six years, including three more surgeries and a number of very trying diagnostic procedures (they had to scrape me off the ceiling after only attempting to complete the hystosalpingogram) just to get up to bat. I was on Lupron—forever, it seemed, just to shut down my system, as I was having problems with recurring cysts. Some were the size of small grapefruits—on my one and only remaining ovary that apparently was "hiding" in scar tissue. My other ovary had to be removed with my appendix as the endometriosis was 'strangling' them both.

After we started the Pergonal and ultrasounds, everything looked OK except the numbers. One thing I learned about medicine—there's a bad way to deliver information and a good way. The bad way was as I experienced it after my unsuccessful hystosalpingogram. My gynecologist took me out into a public hallway—residents and staff walking by, my backside somewhat exposed (and hurting) in my patient gown...and told me my chances for having a child were poor. Needless to say, I was blown away...not only by the information, but how and where it was delivered.

In the end, I was informed by two very caring physicians that my estradiol level, after growing five follicles during the IVF regime, was only just above 100 when it should have been 1600—2000. We did not meet criteria to complete this round. It was then that we

decided to stop completely. At least this time, I had a time and an appropriate place to grieve.

After this one experience, I have to tell you I have mixed emotions about couples who go through the IVF procedure two times or more, regardless of either the cause of their infertility or whether or not the costs are covered by insurance. Yes, it is their choice. But my heart breaks for them. I wish we did not live in a society that tells us we are nothing without our own biological children. Because I know that is not true.

There is a very tasteless "joke" here in Utah...that all a woman has to do to get pregnant is to drink the water. The predominant religion dictates that a woman's worth is based on her ability to bear children. There is still a great stigma attached—even though unspoken—to those who cannot. Having a baby has become very trendy these days—especially for late-in-life parents...having many babies is in line with many churches' teachings.

The sadness and guilt I see in the women who live in my community who have struggled with infertility (and perhaps DES exposure), and thus selfacceptance and esteem, is nothing short of criminal.

Bottomline, I urge you all to please take a long look at what you DO have rather than what you do not. The glass is half full, not half empty...and it might even be overflowing. Please know that your worth comes from within.

O I C E

letters to the editor

Dear Editor,

In reference to the 40-60% reported success rates of IVF clinics: please be careful. There are charlatans out there. Witness the alleged "egg swapping" at the Irvine Clinic, and the incident where the physician was convicted of continually using his own sperm in the IVF process. Unfortunately, medicine is big business, and there are lots of people waiting to take advantage of people who are most vulnerable. Another instance that comes to mind are the Phen-fen weight loss clinics sprouting up on every corner "staffed by physicians."

At the very beginning of our IVF process in 1994, my husband and I were told, very frankly, that the very best clinics were optimally achieving rates as low as 12-15% success and not higher than 20%. These numbers at that time were an honest reflection of clinics that were accepting candidates like myself—who were making the choice to give IVF a try-with full knowledge that success was NOT guaranteed. It is clear that clinics that achieve or report higher success rates are either screening out candidates whose chances are more medically challenging and not easy "wins," or they are lying.

In previous employment, I assisted in the credentialing of physicians for staff privileges at a Los Angeles area hospital. What I learned was while a majority of physicians are above board in their practice, there are a few who jump state lines when a problem is identified, and then set up shop in another state without fear of being caught.

Whether they are caught is dependent on aggressive physician peer review procedures, instituted in most accredited hospitals across the country, and if the problem is reported—in some instances it may not be. The hospital's credentialing unit must also be adept at asking the right questions of other states' professional licensing boards, but if a physician with problems does not report on application that they even had a license in another state, that vital information may be missing and the important questions not asked. There is no national clearinghouse nor independent, non-physician watchdog for tracking physicians/providers who have problems. Perhaps with the advent of the World Wide Web that will change.

So, my best advice is to be very vigilant and very cautious. Call the state professional licensing board in your state and ask if there are or have been any judgments or actions against the care provider you are seeking help from. Ask if the physician is board certified in reproductive endocrinology, gynecology, or whatever medical specialty care you are seeking. A quick phone call to your state's attorney general's office will also be a good start in finding out who in your state licenses physicians.

We all need to do our homework—and not be again victimized by medical marketing ploys or recalcitrant incompetent providers.

Voice of Experience

Dear Editor,
In a column called "Dangerous

deception," Bob Herbert in *The New York Times* of 17 February, tells us of the dangers brought about by the herbicide atrazine, which, while banned in six European countries, is the most widely used pesticide in the U.S.

Is this the DES horror story all over again? A manufacturer is allowed to cause damage and then is not held liable or responsible for its actions. DES was given to millions of pregnant women from 1938--1971. We know that many of the offspring of these pregnant women suffer from a variety of conditions, including increased risk of cancer, infertility issues, and pregnancy problems.

What will happen to those exposed to atrazine? Given the current state of product liability "reform" legislation, and the fact that these manufacturers are not required to prove that their products are safe, we indeed have another case of the fox minding the hen house. Will we have to wait until this dangerous pesticide kills enough people or damages the water supply before action is taken? We still have not learned our lessons.

Stephanie Kanarek Board of Director, DES Action



VOICE

HRT from page 5...

due to heart disease and breast cancer; in the general population, heart disease is more prevalent. The balance of risks and benefits for mortality will be determined largely by the decreased risk of heart disease and the long-term increase in breast cancer among women taking hormones and thus will vary according to the distribution of causes of death in the population under study.

"Nonetheless, we know many ways to lower the risk of coronary disease, but few to lower the risk of breast cancer. Furthermore, in the Nurses' Health Study, women taking hormones appear to be at a greater risk for the development of breast cancer than for death from the disease. The decision to use hormones will be based on

many factors besides mortality, including quality of life and the possibility of living with breast cancer."

A letter to the editor of *The N.Y. Times* expresses the concerns of many women. Judith Armbruster of Chicago writes... "we learn that after 10 or more years of hormone use women face a 43 percent increase in their risk of death from breast cancer.

"How has it become acceptable for medicine to advocate the use of a drug that increases a woman's chances of developing any disease, let alone cancer? When and how did cancer become an acceptable "contraindication" for a drug? What happened to 'First, do no harm'?"

Use Donor Option

If you give to the United Way at your place of work, you can specify that your pledge should go to DES Action. Simply find the line on the card marked "donor option" and write in DES Action. If there is not line, or a card has been omitted from your packet, write in "donor option—DES Action."

Confidentiality Assured

As a courtesy to our members, it is our policy that we never sell or rent your names and addresses to any other organization.

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