V O I C E

A FOCUS ON DIETHYLSTILBESTROL

Fall 1989

#42

European DES Conference in Madrid

by Ellen 't Hoen, DES Aktiegroep, The Netherlands

wenty seven women from seven European countries and Canada took part in the second DES European Network conference this July in Madrid. The purpose of the meeting was to develop DES campaigns for DES-exposed people in every country in Europe. DES Aktiegroep organized the event, helped by funds from the Dutch Health Ministry and foundations like the National Cancer Institute of the Netherlands.

"American Thing"

DES has been used by pregnant women all over Europe. Only in France and the Netherlands, the countries in which DES Action groups are active, is there information for the public about the effects of DES. Since the first European DES conference last year in Brussels, women from Belgium, Germany,

In every country the new DES Action groups get the same response from the medical profession and the government:
"there might be a DES problem but the problem is much more severe in other countries."

Ireland, United Kingdom, Spain and Portugal are spreading information and putting pressure on authorities to take action for exposed people.

It is striking to see how in every country the new DES Action groups get the same response from the medical profession and the government: "there might be a DES problem but the problem is much more severe in other countries." This was no news to DES Aktiegroep. When we started, we were told time after time that the DES issue was a real "American thing". It was much worse overseas, we should not worry. Anita and I were each

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ere is the poster to be put up in buses and subways in 65 cities all across Canada, the work of our affiliate DES Action/Canada. The Hon. Monique Begin, former Minister of National Health and Welfare (1977-1984) is the chair of

the campaign, which will alert Canadians from coast to coast about DES. DES Action/Canada is asking the corporate sector for sponsorship to cover the printing and installation of the posters over the next year.

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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** ** medical update

Prostate Health Care

s DES exposed who understand the importance of regular checkups, we want to bring some important material to your attention.

Prostate cancer will strike nearly 103,000 American men and kill 28,500 this year. It is the third most fatal male cancer, afflicting one in ll men during their lifetime. A recent national survey, however, shows that three-quarters of American men are not personally concerned about getting the disease. That means too few men are getting a simple exam that can detect prostate cancer in its early and curable stages.

Awareness of prostate cancer among men today just about equals that of breast cancer among women ten years ago. While we face similar challenges with prostate cancer, it is a more difficult battle since men are more reluctant to express their fears and talk about the disease among themselves.

You can get the free educational brochure on prostate cancer by a toll-free call to the National Cancer Institute at 1-800-422-6237.



The DES Action Voice is published quarterly by DES Action USA 2845 24th Street San Francisco, CA 94110 Program Director: Pat Cody Board Officers
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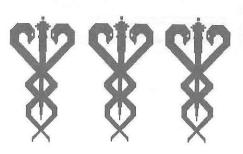
Printing: Inkworks, Berkeley, CA

TRANSITION

by Fay Cohen, DES Action, N.Y.

Recently while going through my files searching for the elusive paper I wanted, I came across a copy of the very first DES Action VOICE. It brought back so many memories—fears of the unknown which plagued me at that time.

In retrospect (and still on cloud nine after the birth of my second grandchild) I started thinking about the DES mothers who have shared their own feelings with me over these past ten years. With these thoughts I have written the following, which I would like to dedicate to all of us very special ladies.



MADRID from page 1... told, by different doctors, that we were the only DES daughter in the Netherlands.

Europarliament

The beginning DES Action groups have received tremendous support from the European Parliament in a resolution on DES that was passed in June. The resolution pleads for national awareness and information campaigns for both the public and doctors. One of the speakers at our meeting, Annemiek Onstenk, who works for the Women's Bureau of the Green Alternative European Link (GRAEL) in the

My Wonderful Transition— From DES Mom to DES Grandma

I've lived through days and nights of fear, The unknown risks for one so dear. I watched her grow from tot to teen, and wondered how I'd find the means to help her through her toughest days. Somehow, I managed to find my ways.

The years passed by—she met her mate; The joy and excitement of the wedding date— Before you know it, she's leaving town It's time for her to settle down.

Now I wait and wonder and pray
Will she have children of her own one day?
Time passes on, and praise the Lord
She's pregnant, on bed rest and very bored.
The high-risk scene we must sweat out
But finally, no room for doubt—
She reaches term: her baby's here.
Have you ever seen anything quite so dear?

Oh yes, I've lived with times of fear—But thankfully, I am still here.

Parliament, stressed the fact that this resolution really means a recognition of the DES issue in Europe.

Dilemma

One of the most discussed dilemmas for the participants was the timing of the publicity on DES in countries in which there is no awareness whatsoever about DES. This means that the medical profession has no knowledge about what to do with DES exposed women. Raising awareness could cause harm because DES daughters do not have access yet to expert gynecologists and might receive wrong and even dangerous treatments. On the other hand, postponing awareness campaigns means that many DES daughters will never find out about their exposure and this also carries risks. It is also the task of a DES Action group to provide the information to the medical profession and develop a referral list in every country.

Gunilla Kleiverda, gynecologist and a member of the Dutch DES Gynecology Network, gave a presentation on how to do a proper DES exam. She also gave an overview of the latest medical research on DES. At the request continued on page 8

Prevention of Cervical Cancer

🛮 rom Australia comes a 🛾 new booklet, "When A Pap Smear Isn't 'All Clear' . . . " written by the Women's Health Information Resource Collective in Victoria. Because DES daughters have a greater risk for cervical cancer, we think our readers will be interested in this section on prevention.

"It is our view that the following changes need to take place before we, as women, can feel confident that we can act in a way that gives us a maximum chance to prevent cervical cancer.

We need more research and more knowledge about the causes of cervical cancer so that prevention strategies are more sensible to us.

Evidence is suggesting that there is a link between the health of a cervix and something to do with sex. Women whose sexual partners use barrier methods of contraception seem better protected against cancer, and may have a better chance of cervical cell abnormalities regressing to normal. If this is the case, we need the cooperation of male sexual partners in sharing the responsibility not only for contraception, but for the health of our bodies.

Changes in attitude

If the cause of cervical cancer is sexually transmissible, we need a change in the attitude of doctors, researchers and writers so that we are not made to feel guilty, dirty or irresponsible. Because risks of cervical cancer may increase with the number of heterosexual partners, many women are made to feel that their cervical cell abnormalities are a

We need more research and more knowledge about the causes of cervical cancer so that prevention strategies are more sensible to us.

consequence of their own sexual history, and feel bad because of it. The sexual history of male partners is rarely even mentioned, even though women who have had only one or two sexual partners are at risk from men who have had multiple partners.

It is known that women who start having heterosexual sex at a very young age are at higher risk of developing cervical cell abnormalities. But this message is often interpreted to us in a way that makes us feel guilty about our sexuality or our morality. If it's the case that early sex puts us at higher risk, it is much more likely to be because of the physiological changes taking place in our cervices in the early part of adolescence. The squamo-columnar junction is more likely to be exposed to change-causing agents because it spills further out on the surface of the cervix at this age. Using this perspective, the link between teenage sex and cervical cancer has little to do with morality, or judgments about women's right to express themselves sexually Rather, it reflects the poor deal young women get from health information services and education.

Human Papilloma Virus

Certainly we need more clear information about the link between the Human Papillomavirus and other cervical cell abnormalities. Since so many women with dysplasia have also been infected with HPV, the link seems strong. There is no apparent link, however, between cancer of the penis and HPV. The problem is perceived as women's problem—and it is us who are left with dilemmas if we have genital warts.

There is debate and concern within the medical community about the real implications of HPV. Some doctors want to treat all women with even minor cell abnormalities associated with HPV—and feel that some of these abnormalities might grow more rapidly or aggressively toward true cancer, especially in younger women. Some are suggesting that biopsy, laser or cautery even protect us against future reinfection with HPV. On the other hand, some researchers are suggesting that minor cell abnormalities may just reflect the HPV infection alone-and shouldn't be treated unless they persist for a long time. We are receiving multiple and confusing messages (or no messages at all) about the implications of HPV. If there is a link between true cancer and some strains of HPV, we need to see more money being spent on finding ways to tell which strain we've been infected with—and more money spent on explaining it all to us!

External factors

We need more information about the link between the development of cervical abnormalities and our immune systems to help explain why some women are more at risk than others. In the

past, there has been a suggestion that cervical cancer is more prevalent among poor women—but the way this information has been expressed has left many women with cervical abnormalities vulnerable to feeling less than equal with other women. We need, instead, to have more information about the links between poverty, diet, job conditions, environment, comfort, stress and cervical cancer—and we need ways to act on these external factors!

We need to have reasons to believe that pharmaceutical companies and others are not putting

We need more
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stress and
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on these external factors!

our health at risk in the drive to make profits. Menstruation, menopause, pregancy and our ability to get pregnant has meant that women have been swamped with chemicals and hormone treatments. Drugs like the oral contraceptive pill, Depo Provera (the injectable contraceptive), DES and synthetic estrogens have been used to 'treat' us even though the problems we experience are sometimes social, not medical, problems. There may be a link between some of these 'solutions' and an increasing incidence of cervical abnormalities. If that is the case, it is a high price to pay for being women.

Under-served Women

All women need to have confidence that we can get access to decent medical and information services. There is a lot of talk in the medical literature about 'non-compliant' and 'unscreened' women. There is less talk about ways to make services properly available or comfortable to us. Some women are at a particular disadvantage, even though we make up a sizable part of the community:

- Women who don't speak
 English have difficulty finding doctors who are from their own community.
- Women whose culture or religion means that they need to have a Pap smear done by another woman, or an older doctor, or an understanding health worker, do not have equal access to health services. Most Pap smears are still done by doctors, and most doctors are still male, from an Anglo background or from the middle class. Many have inherited sexist and racist attitudes
- Many older women feel acutely uncomfortable or embarrassed about having a smear taken, especially if they have had an experience with a doctor who doesn't treat their vagina gently. Some older women are under the impression that they don't need to have a smear after they've been through menopause—and some doctors reinforce this idea.
- Some young women, on the other hand, have a belief that cancer of the cervix is an 'older women's disease' that doesn't concern them. They too sometimes suffer or fear doctors' judgments about their sexuality.
- Lesbians are frequently led to believe that they do not need to have Pap smears (despite

many lesbians' past heterosexual history)—and have difficulty finding health professionals who are not bigoted.

 Women with disabilities still face prejudice about their rights to be sexually active, and in some cases, don't have much choice over which medical services they use.

 Women who have had hysterectomies or partial hysterectomies are left confused about whether they should continue having Pap (or vault) smears.

 Because such a song and dance is made about needing to have Pap smears if you're sexually active, many women who have not been sexually active for a long time don't relate to the need for regular smears—regardless of their history.

 Housebound women have little access to screening services
 —and rural women are more restricted in their choice of doctors.

The list of reasons we don't have Pap smears is long and our tolerance for bad experiences is naturally and understandably short. It only takes one or two bad experiences of a Pap smear to put any normally sensitive woman off for a very long time. These factors have to be attended to by medical services, medical educators, policy makers and funding bodies before 'screening' programs to prevent cervical cancer can be seen to have much relevance for us all.

Even then, we need to have confidence that the screening programs we participate in are worthwhile. Pap smears are not always accurate, and we need encouragement to have repeated smears at the right intervals. But we also need to know that testing laboratories have strict qual-

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letters to the editor

Dear Editor:

I am a DES daughter. I am writing to tell about my experience with bringing legal action against Eli Lilly. The point of writing is to warn against some of the pitfalls in these lawsuits, and to encourage others to not give up when the going gets rough. It will get rough, for the drug companies are determined to fight us all the way.

I first found out about my DES exposure in 1974. Years later, after many attempts at pregnancy, one unsuccessful pregnancy, and too many "we don't knows" from numerous doctors, I finally heard the words from Dr. Dodson at Duke Medical Center—I would, in all probability, never conceive a child without extraordinary methods. And even if a pregnancy was achieved through extraordinary methods i.e. GIFT or IVF, I was faced with the possibility of not carrying the child to term, based

on the already unsuccessful pregnancy, and the condition of my reproductive tract due to DES exposure, endometriosis, and scarring which had occurred from cryosurgery for the DES problems, surgery for the endometriosis, etc.

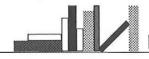
After many, many days of thought, I decided to commence legal action. The end result was not exactly what I had hoped for either in a personal victory, or in a group endeavor. It became apparent to me that the law firm I had chosen found that the case was going to be too hard to fight for a number of reasons. There were statute of limitation problems arguing time of discovery, there were logistic problems of where we could take the case due to archaic product liability laws. There was the absence of "proven" medical facts surrounding DES patients. Probably most frightening was the battle against a huge drug company

who has hired and trained attorneys to be the most aggressive, the most diligent in winning, sparing no expense or tactic to slaughter their adversary. I began to get conflicting reports from my attorney as to testimony we could expect from the doctors to whom he had talked, about legal remedies, about costs his law firm could not absorb, and about the terrible emotional drain these lawsuits put on families. Sadly, I even found that my husband and I stood on two different sides of the battle since he could not fully understand why I had to do this

My "victory" was a small settlement which did not begin to cover even the costs paid to my attorneys. But, while it does not show an absolute victory, perhaps in some small way it will strengthen future lawsuits by increasing the number of actions Lilly and others have settled. In other words, I lost the battle, but maybe it would help win the war. This was not the victory I had hoped, but it was better than doing nothing, or worse, dropping the lawsuit when it looked like I would never win—that's exactly what the drug companies want us to do.

While I know this was the right decision for me, I felt I had let my sisters down even though an attorney friend of mine supported my decision and my thoughts on the "victory on paper." I feel strongly about combining all our energies, not letting these big drug companies

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books

nfertility: Problems Getting Pregnant is the latest in a series of resource books written by the Vancouver Women's Health Collective. In just over 200 pages they cover causes of infertility, the infertility workup, new reproductive technologies, adoption, alternatives to parenting, feelings and social pressures.

Other books in the series include *Talking About Periods;* Avoiding Pregnancy; Miscarriage: You're Not Alone. Each of these books costs \$12 Canadian plus

\$2.50 postage and must be ordered directly from:

Vancouver Women's Health Collective 1720 Grant St., Suite 302 Vancouver, B.C. V5L 2Y7 Canada

Since they would have to pay bank transfer charges if you send a personal check, please get an international money order from any post office. The Canadian dollar is less than the U.S. dollar, so \$14.50 Canadian equals \$11 U.S.

Remember, letters to Canada take 30 cents postage.

LETTERS from page 6...

keep pushing. It is so difficult for me to understand how they spend millions to fight the people they have harmed. How much more logical it would be (and probably more economically beneficial) if they would just direct all that money to helping with the DES problems!

My final word to anyone who is contemplating a lawsuit: make sure your attorney knows and has tried DES cases before. Check with your doctor about information he has exchanged with your attorney (in my case what my doctor actually said and what my attorney told me he said were two different things!). Be prepared for a bloody battle that will drag every particle of your past before not only you, but your husband and a jury everything from your job histories to your sexual acts will be graphically described. Make sure your attorney knows about all the victories already scored—this is one area where we didn't have a lot of input. I began to wonder if anyone other than Joyce Bichler had won. It is clear to me that

the drug companies will stop at nothing to keep us from fighting. It seems more obvious than ever "united we stand, divided we fall." Every victory, no matter how small, is important to the end result. Remember the goal for all of us; it's not just an individual battle.

T.P. North Carolina

Dear Editor:

I am a DES daughter and now mother of two girls. I'm writing to remind other DES daughters to always have their pregnancies regarded as "high risk." I especially want to reach those daughters who were lucky enough to have had uncomplicated first pregnancies.

My first daughter was born at full term after a relatively uncomplicated pregnancy. I did have hypertension and toxemia but nonetheless my daughter was only 2-1/2 weeks early. So when I became pregnant again I prepared myself for the possibility of having high blood pressure again but generally assumed all would go well again.

I started cramping at 18 weeks, went on oral Ritodrine and bedrest at 20 weeks, was hospitalized at 27 weeks with contractions that could not be controlled by oral medication, and was put on IV magnesium sulfate at 28 weeks. I stayed hospitalized for 6 weeks and went on to deliver my daughter 33-1/2 weeks into my pregnancy. She was on a respirator and other forms of supplemental oxygen for one week but luckily after that she did great and we brought her home a month before my due date, weighing 5-1/2 pounds.

I had never expected something like this. I knew DES daughters were at risk for preterm labor but had thought that since it hadn't happened the first time, things must be all right and it won't happen now. This made it all the more hard for me to deal with all my limitations and bedrest. Talk about denial!

I think, therefore, it is crucial for pregnant DES women to obtain the type of "high risk" care we require and to be well educated as to the signs and

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Join DES Action!

Yes - I want to get the answers about DES. Enclosed is my membership.

☐ Benefactor: \$1000 and above	☐ Supporter: \$150		
☐ Sustainer: \$500	☐ Friend: \$75		
☐ Associate: \$250	☐ Subscriber: \$50-\$25 (sliding scale)		

All members receive The DES Action Voice quarterly. Those at the \$75 level and above receive additional annual reports on DES Action's work and progress.

	1 0
☐ I would like to start my membership of \$	through the Pledge Program (\$75/year or more).
Enclosed is my first \(\pi \) quarterly or \(\pi \) semi-annual	I payment (choose one) of \$

I am a: DES Daughter	DES Son	☐ DES Mother	□ other
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MADRID from page 3...
of a group of interested Spanish
gynecologists, she repeated her
presentation in a clinic in Madrid
that same night. The doctors
recognized colposcopic findings
shown on her slides because they
had seen them in their patients,
But, up to now they had not been
aware of the relationship to DES
exposure.

On British TV

The last day of the meeting was taken up with planning for the future. Each country made their own plans to trace and inform DES exposed. The British groups will be the busiest for the next few months. Because of their activities, Thames Television got interested and will be showing the first British documentary on DES in October. The

station will offer free informational pamphlets to viewers.

The third meeting of DES Action Europe will be in Ireland in 1990, and form the starting point for a national informational campaign in Ireland.

CERVICAL from page 5...
ity control over the way our
smears are assessed—and that
governments are prepared to
make sure that quality is guaranteed.

Finally, we need to have a sense of control about what is happening to us when we have our cervices tested for healthiness. Having our own records of tests, having information so that the fear of cervical cancer is taken away, and knowing that the feelings and knowledge we have about our own bodies won't be disregarded

by doctors, is good prevention against cervical cancer."

LETTERS from page 7... symptoms of preterm labor. Fortunately I had insisted on biweekly visits and was very aware of my preterm contractions, but this might not be the case with all women.

I would like to add one other note. Just because DES daughters should receive high-risk prenatal care does not necessarily mean it is required for the actual delivery. Even though I was early and high risk, my doctor worked with me to have the type of natural, non-intervention delivery I so wanted. It was a wonderful end to a very difficult pregnancy.

C.B.

Massepequa, N.Y.

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