THE DES ACTION VOICE

A FOCUS ON DIETHYLSTILBESTROL

Summer 2002 • #93

HRT: Hazardous to Women's Health

Study Shows Long-term Use Increases Risks for Disease

by Pat Cody

WE have just had the fourth report this year linking the use of HRT to cancer and other health risks. This newest study from the National Cancer Institute and reported in the *Journal of the American Medical Association (JAMA)* for July 17 tracked over 44,000 women for 19 years. It revealed that those who took estrogen for 10–19 years had an 80% higher risk of developing ovarian cancer.

This corroborates an April article in the *Journal of the National Cancer Institute* describing a study in Sweden of 655 epithelial ovarian cancer patients, compared with 3,900 population controls free of cancer. They found that those cancer patients who had ever used HRT, or HRT with sequentially added progestins (HRTsp) had elevated cancer risks. The exception to the risk was those women who had used estrogens continually supplemented by progestins (HRTcp).

Earlier in 2002, and reported in our Spring issue 92, *JAMA* (February 13) wrote about a significant increase in breast cancer in a group of post menopausal women aged 50–74. Those on HRT for over five years had a three-fold increase in primary invasive breast cancer.

The third challenge to HRT came early in July when the federally funded Women's Health Initiative announced a halt in their HRT long-term study. This is a dramatic action, taken because of increased risks for invasive breast cancer, coronary heart disease, stroke and blood clots among the postmenopausal women aged 50-79 years with an intact uterus. The trials had been at 40 clinical centers in the U.S., and involved dividing the group in two. One got daily doses of Prempro (Premarin and progesterone) and the other a placebo. The trial designed to go for 8.5 years but was stopped on May 31 after 5.2 years of follow-up showed these risks:

Coronary heart disease	29% increase
Stroke	41% "
Blood clots	100% "
Invasive breast cancer	26% "
Total cardiovascular disease	22% "

Benefits listed were a 37% drop in colorectal cancer and 24% reduction in bone fractures.

The researchers point out that these alarming percentages of risk do not translate into high numbers of injured women. They clarify that in a group of 10,000 women on HRT, there will be 7 more coronary heart disease events, 8 more breast cancers, 8 more strokes, and 8 more blood clots. Adding all these events together over the years of the trial, the excess number of events in the HRT group totaled 100 per 10,000, or 1%. This is a small risk—unless it happens to you. In an editorial in the July 17 issue of the *Journal of the American Medical Association (JAMA)* that reported these results and decisions, Drs Fletcher and Colditz of the Harvard Medical School wrote

"The whole purpose of healthy women taking long-term estrogen/progestin therapy is to preserve health and prevent disease. The results of this study provide strong evidence that the opposite is happening for important aspects of women's health, even if the absolute risk is low. Given these results, *we recommend that clinicians stop prescribing this combination for long-term use."* (emphasis added)

The National Women's Health Network responded to this news with a sharp statement from their director Cynthia Pearson:

"The Women's Health Initiative has driven a stake into the heart of hormone replacement therapy (HRT). But the real question is: why did we ever believe that HRT prevented disease?

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INSIDE

Update on DES Internet Listservs

by Sally Keely (aka "DESxposd")

THERE are now several DES e-mail lists.

DES Action members with e-mail access are invited to join the DES Action Listserv, DAL. The purpose of this listserv is to allow a direct e-mail link between DES Action and our members. This forum is primarily for information sharing, for instance: Legislative alerts, Press releases and news updates, Event announcements, e.g. DES Symposiums, Information from upcoming DES Action Voice newsletters.

This low volume list is a benefit of membership. Only current DES Action members may participate. To subscribe, send e-mail to Sally Keely, the list owner, at DAL-owner@lists.perilpoint.com. Please include a statement that you wish to join DAL and the full name under which your current DES Action membership is listed. Note: this list has recently moved to a new server, so these are new subscribe directions. All 95 previous list members have already been transferred over to the new site. If you have any questions about the list, please contact Sally.

DES daughters should check out DES-L, the DES daughters listsev and online support forum at http://www.surrogacy.com/online_support/des/. To join the listserv, complete the online application and get ready to share support and information with 1000 other DES daughters!

DES sons will want to join the DES-Sons list for confidential discussions of issues related to DES exposure in males. This list was developed in conjunction with DES Action. To subscribe, send e-mail to des-sons-subscribe@yahoogroups.com. The website for the sons' network is http://groups.yahoo.com/group/des-sons.

The DES-Family list welcomes all DES-exposed, their family, and friends. To join, e-mail listserv@sact.com with only the command "subscribe des-family" (without the quotes) in the body of the message.

Charli@egroups.com can help if you have questions.

Lastly, announcing the newest DES related listserv, DES-Pregnancies. DES daughters who are pregnant, trying to conceive, or contemplating pregnancy are invited to join via the list website http://www.onelist.com/subscribe/despregnancies. You will need to register with onelist, if you aren't already. Contact ladonnakat@aol.com if you have trouble subscribing.

DES Action Affiliates and State Contacts

DES Action Affiliates

Each affiliate was created and nurtured by volunteers. Write to them if you want information or would like to volunteer.

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State contacts participate in national projects organized by DES Action. Contact the national office if you would like to find out about our national projects.

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San Diego, CA
Grand Rapids, MI
New Jersey
New Mexico
Ohio
Oregon
Texas

DES Action International

Australia
Belgium
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England
France
Ireland
The Netherlands
New Zealand

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Notes from Nora

CDC's DES Update Set to Begin Soon

As regular readers of this newsletter know, the Centers for Disease Control and Prevention (CDC) have been engaged in a planning process for a National DES Education Program for the past two years or so. DES Action, along with many other consumer and health care provider organizations, has been an active participant in this planning process.

At long last the CDC is ready to launch this program, now titled "CDC's DES Update." This title, like everything else in the program, was developed based on the results of focus group research and interviews with many DES-exposed people and their health care providers. The CDC found that many health care providers dismiss DES as an old issue, and hope that the words "DES Update" will alert them to the fact that there is new information they need to know. Use of the CDC reflects the high credibility given to this public health agency.

CDC's DES Update is set to begin this fall, with simultaneous efforts to reach out to health care providers and members of the public. DES Action volunteers will be organizing meetings, contacting local media, and utilizing other avenues to help the CDC spread the word about the Update. DES Action leaders will also be closely involved in helping to generate as much press about the program as possible.

The CDC is establishing a toll-free hotline and information clearinghouse, so that anyone seeking information about DES can phone and request that free literature be sent to them—or to their health care provider. There will also be a new DES website. As a member of DES Action, you will receive the complete packet of information from CDC. Look for a letter from us announcing this mailing, followed by the packet in your mailbox. If you want to help distribute DES literature, you will be able to call the CDC and request additional packets. We will give you the toll-free number and website address as soon as they are up and running.

We are looking forward to sharing the DES Update with you and your health care providers.

"The CDC found that many health care providers dismiss DES as an old issue, and hope that the words "DES Update" will alert them to the fact that there is new information they need to know."

Recently a member wrote a note on her renewal card, asking why we have so much bad news in our newsletter. She found it depressing. In thinking about what she wrote, I recalled reading an analysis written by Ed Wolf, who is the husband of one of the leaders of the "DES Tall Girls" group in Australia. (Note: the Tall Girls are women who were given high doses of DES during adolescence to stunt their growth. They have since developed many health problems similar to those experienced by DES daughters). In the February, 2002 issue of DESPATCH, the newsletter for DES Action in Victoria, Australia, Ed Wolf writes:

"No consumer health group is ever formed in positive circumstances. Negative medical experiences and their outcomes are the point of coalescence for its formation. Collecting this negative corroborative testimony can potentially overwhelm those who take on the issues that are raised ...(However) by sharing so many narratives from other Tall Girls and by recounting their own stories so often to the media, the women located their own experience within a wider context. This engendered not only a sense of responsibility to the group narrative rather than simply one's own, but also made one's own negative experience seem less central.

"Secondly, by the time the women began to engage in representations to government and the medical profession, their ownership of their narrative was so complete that they could confidently assert their status as 'the primary stakeholders' in any research that was to be undertaken.

"The power of testimony relates to how you participate in your narrative: with what atti-

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"Pharmaceutical companies have used statistical smoke and mirrors to tout unproven benefits, minimize risks, and mislead physicians into being an unsuspecting marketing force for a regimen that harms healthy women. There was never one single clinical trial that showed that HRT prevented cardiovascular disease or stroke. This is not a story of science moving sedately forward, carefully adding pieces to a puzzle before making recommendations to patients. This is a story of the corruption of the medical and scientific community. The belief that hormones are good preventive medicine has been a triumph of marketing over science...

"Spinning science has to stop. HRT is not the only therapy being over-promoted by drug companies to healthy people. Pharmaceutical companies have bought physicians, have bought scientists, and have bought clinical medicine. Science must be separated from advertising."

How right Ms Pearson is. Two days after the news on stopping the study was reported, Melody Petersen of the *New York Times* wrote that Wyeth-Ayerst has sent 500,000 letters to doctors and other providers

"urging them to consider when they talk to patients the 'critical role' that one of its products, Prempro, has in relieving the symptoms of menopause...The letter provides a glimpse at how Wyeth hopes to hold onto sales of Prempro and its related hormone therapy drug, Premarin, which generated more than $2 billion in sales for the company last year...Wyeth appears to be trying to keep any loss of sales limited to women who take Prempro for four years of longer. To reduce fears, Wyeth also points out that the risks of breast cancer and heart problems had already been found in other studies and included in Prempro's labeling."

On its editorial page, under the heading of "Hormone Therapy Woes," the *New York Times* advised its readers.

"The news keeps getting worse about the value of hormone replacement therapies for postmenopausal women. Less than three months ago an international panel concluded that there was little evidence to support many of the presumed benefits of the treatments. Now federal health officials have halted a large study of hormone replacement therapy because the regimen used, a combination of estrogen and progestin, was doing more harm than good when taken for several years. The action has been met with shock and disbelief by many women and their doctors.

"The danger to any individual woman appears very slight. But this discouraging saga offers a sobering lesson in how aggressive marketing by the drug industry and a fervent desire for medical miracles on the part of patients and doctors can propel use of a drug far beyond that justified by scientific data..."

This last paragraph applies equally to the DES story. A study by Dr. James Ferguson in 1953 and reported in the *American Journal of Obstetrics and Gynecology* concluded that stilbestrol during pregnancy with his study group "had no effect on preeclampsia, prematurity, fetal weight and survival, or the size of the placenta." A discussant of the article, Dr. R.R. Greene, concluded that "Dr. Ferguson has, I believe, driven a very large nail into the coffin that we will use some day to bury some of the extremely outsized claims for the beneficial effects of stilbestrol."

Oh that that burial had taken place. DES continued to be given to pregnant women in the U.S. for 18 more years. Are we going to see a blithe continuance of HRT prescription?

We have small satisfaction in saying "we told you so." Those who should hear our message will continue to ignore us as they have in the past. We feel anger and grief over the disease and hardship caused totally unnecessarily by the pharmaceutical companies and the many physicians who listened to them. We do not need vindication, but are gratified that at last the dangers of HRT have been broadcast far and wide.

Prescribing estrogens to DES exposed women—mothers and daughters—has long been a concern of ours. In the first year of this newsletter, Summer 1979, we had an editorial on "DES Daughters and the Pill." Here is part of that article:

"Many private physicians have advised DES daughters not to worry about taking birth control pills. They say, in effect, 'We have no proof that taking the pill will be harmful,' and they imply that those who advise against the use of birth control pills are not basing their opinions on scientific evidence.

"We look at this issue from another view: we have no proof

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that taking the pill is safe. There is no scientific evidence that it is safe. Further, no long term studies have been done on DES daughters and pill use. A number of prestigious groups and well-respected researchers in the medical field support the idea that DES daughters not use birth control pills. Here is a sample of quotations:

- Former HEW Secretary Joseph Califano: In a press release on DES, the Secretary called it "prudent" for all DES mothers or daughters *"to avoid any further use of DES or other estrogens* because the carcinogenic effects may be cumulative" (emphasis added).
- The Federal DES Task Force of the Department of HEW: "In view of the lack of Information on long term effects of estrogens in these women (DES daughters) the committee felt that *oral contraceptives and other estrogens should be avoided.* The use of estrogens requires careful consideration by the patient and her physician of alternatives." (emphasis added).
- A World Health Organization Scientific Group: "At least 70% of women exposed in utero to diethylstilbestrol have vaginal and cervical adenosis. Findings of squamous metaplasia, dysplasia and carcinoma in situ on the margins of the areas of adenosis have raised anxieties about the potential for malignant squamous cell carcinomas in these women...Combination oral contraceptives may lead to increased squamous metaplastic activity, and therefore probably should not be used by women with cervical or vaginal adenosis...It is inadvisable to prescribe steroid contraceptives for women with vaginal adenosis."
- Furthermore, a recent medical journal article which studied the effects of DES on mice concluded that the results from these studies "call attention to the possible risk of estrogen growth-stimulating effect on the DES-induced adenosis and indicate the need to avoid estrogen exposure, including estrogen-containing oral contraceptives, by such individuals."

In the years since then, as daughters have aged, taking hormone replacement drugs is increasingly urged on them. To counter this barrage of drug company and physician pressure we have given our members reports on many studies. Almost every year we have informed them of new research. While this work was done with women in general, not DES mothers or daughters, the caution flags were everywhere. Altogether we have published 24 articles on hormone treatments, right up to our last issue, Spring 2002, which featured the report on increases in breast cancer risks for HRT users.

What can we do? We cannot retreat into cynicism. Now we have the research to prove "as far as we know it is not safe." We can talk to friends, neighbors, co-workers, and ourselves if necessary. We can point to other remedies for osteoporosis that are more effective. We can learn about non-hormone relief from hot flashes by reading articles like "Hot Flash! Healthy Ways to Turn Down the Heat" that we had in our Winter 2000 issue 83 (send us a stamped envelope if you need a copy).

Perhaps we can drive a nail in the coffin of the provision of dangerous drugs to unsuspecting consumers. ■

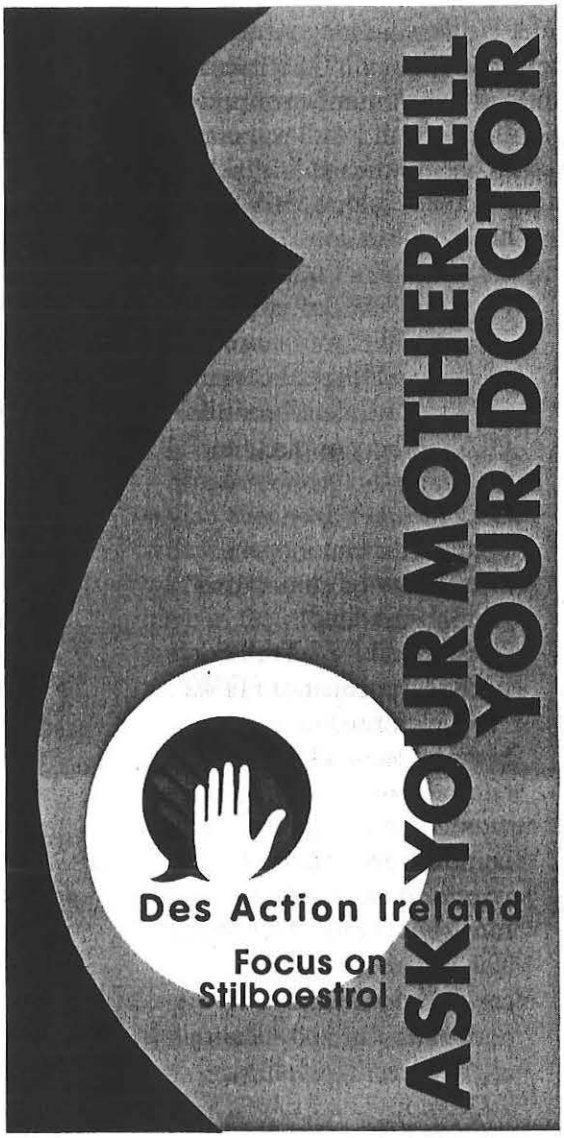
NOTES FROM NORA from page 4...

tude? For what purpose? By which means? Tall Girls participated with a positive attitude, for the benefit of the group and beyond, by employing the channels available in a democratic society to present their case."

Much of the same can be said about DES Action, in my opinion. Yes, what happened to us is negative. Just as the dramatic news now emerging about hormone replacement therapy (not news to us, by the way) shows, too much exposure to estrogens is not a good thing. It causes diseases and health problems. This bad news would be there whether we existed or not. What DES Action offers is a way to do something about the bad news: we organize, we advocate, we insist that there be funds devoted to good research and to the education of our health care provider so that we can get the best medical care. And that, I believe is good news indeed. ■

How we got our new information leaflets

From Daphne Passmore, DES Action Ireland



THIS is a story to illustrate how some things in Ireland happen; perhaps it's the same in other countries, perhaps not.

In April 2001, in advance of the Washington DES Colloquium, DES Action in Ireland issued a press release focusing on the medico-legal aspects of DES exposure as it was figuring high on the American agenda. Carl O'Brien, a reporter from the *Irish Examiner* national daily, and previously unknown to us, took up the story and it made the front page. At the same time, Carl raised the DES issue with the Minister for Health at a press briefing about an altogether different subject. Carl told us that the Minister had agreed, there and then, to meet DES Action.

As a direct consequence of the newspaper story, the national radio station took it up on the same day. Dr. Mary Wingfield of the Irish DES clinic gave an interview on the lunchtime news bulletin. Although the press release focused on the legal aspects, the opportunity was taken to raise the issue of DES exposure in a broader sense in the interviews that followed.

Later on the same day that the article appeared, I gave another interview on the evening news programme. This was followed by a number of local radio interviews during the next few days.

While Aislinn Ni Eifearnain, the Chair of DES Action Ireland, and Colette Egan, the Treasurer, were winging their way to the Washington meeting, I as the information officer was left to deal with the fallout from all the publicity. In the weeks that followed, there were hundreds of phone calls to the information line. Many of them were from women who were hearing about DES for the first time...It was great to have reached so many people as a result of one press release although Dr. Wingfield was under pressure to add extra DES clinics at the hospital to screen the women at risk who came forward.

When we had time to catch our breath, we wrote to the Minister for Health, Micheal Martin, requesting a meeting with him and reminding him of what he had said to Carl. A meeting was arranged for July and Aislinn and I represented DES Action. The Minister had present a personal assistant and a senior official from the Health Promotion Unit of his department. The first thing he said to us was, "What do you want me to do?" and we told him. We had an excellent discussion with him and we felt he had been well briefed on the DES issue.

While the matter of his Department's future role in publicising the DES issue, and dealing with the response that any publicity would undoubtedly initiate, was left open for future discussion, the Minister offered to revamp our information leaflets, pay for the printing and distribution of same, and fund our website. Needless to say, we came away from the meeting very pleased. DES Action Ireland now has a website, new leaflets, and a Minister for Health who is sympathetic to our cause. Not bad for one press release! ■

Justice at Last

AFTER a trial delay of over ten years, two cancer daughters in France finally had their day in court. Here is an excerpt from the web site of the British Medical Journal for 8 June, reported by their Paris correspondent Alexander Dorozynski:

"Two women who developed cancer after their mothers took the drug diethylstilbestrol have won their case against the pharmaceutical company UCB Pharma.

"The initial payment to the women will be followed by an evaluation of the "moral consequences" of their injuries and a final settlement payment to be set by the Court."

"The company continued to market the drug until 1977, six years after it was found to be associated with an increase in vaginal cancer in girls and young women whose mothers had taken it, and six years after it was taken off the market in the United States. This is the first successful suit involving the drug in France.

"The court ordered the company to pay each of the women 15,244 euros as an interim payment, until full damages are assessed...The first lawsuits were begun in 1991 by 10 women suffering from cancer of the vagina or uterus. The lengthy legal procedure was slowed down while many scientific documents were translated into French and a four-year expert study was carried out into the drug. The delays discouraged most of the plaintiffs, and only two of them persisted: Natalie Bobet, now 33 years old, and Ingrid Criou, 28.

"But now that the two women have won their case, other cases may be revived and new complaints registered. Martine Verdier, the plaintiff's lawyer, said that she had about 30 cases waiting on her desk."

The decision was made on May 24 by the Court of Grande Instance in Nanterre , and the initial payment to the women will be followed by an evaluation of the "moral consequences" of their injuries and a final settlement payment to be set by the Court.

The Paris daily *Le Monde*, in a story on May 25, interviewed several DES daughters. They began their story with this paragraph:

"From 1948 to 1977, a synthetic hormone, Diethylstilbestrol (DES) was frequently prescribed to almost 160,000 pregnant women, in order to prevent miscarriages. Children exposed in utero to this drug have genital system anomalies today, even sometimes cancer..."

and continued with interviews of some DES daughters:

"It was February 4, two years ago. I was 29 years old." Without hesitation, Catherine Petit can still today date the entrance of DES in her life. That day, some vaginal bleeding made her go to a Parisian hospital. They found cancer of the cervix. She found out about the existence of DES that her mother, Paule, had forgotten "In 1971, I was pregnant after I had a late miscarriage," said Paule, a retired teacher. "I took a lot of things at that time, very conscientious." From her regular doctor, she found about the DES. "In my file was the prescription for the DES left by my previous doctor who never told me anything. Nevertheless, he must have realized before he left...it was really a silent conspiracy""

"Her daughter Catherine...not the type to complain about herself. Tears come to her eyes, however, when she speaks about her months of chemotherapy, radiotherapy, curitherapy, and the five hour long operation..." Once the fight against the illness is gone, there is still a feeling of injustice and revolt against those people who, like in the contaminated blood scandal, used the drug while knowing it." Catherine waits for reparation, thinking even to go in court. "Right now I am repairing myself, with my psychiatrist who I pay. It is not fair. Neither I or my mother have behaved badly." Her mother is revolted when someone asks if she is feeling guilty. "We, the mothers, are not guilty, but victims!" ■

Letters to the Editor

Dear Editor:

I have to add my mom to the list of DES mothers with breast cancer. Fortunately she is one of those that takes her annual physical seriously and gets an annual mammogram, so, the cancer is smallæ...She is doing the pulmonary stress test this morning and then seeing a radiology oncologist to decide. What was interesting, and SAD, when she went in for the follow-up mammography, I went with her and mentioned that she was a DES mom, and the radiologist and tech had no idea what I was talking about. I told them a basic bit of information and they nodded their heads and said "oh" so I said that it needed to be on her record, and that it absolutely needed to be on any biopsy slide.

Which it was, I saw the biopsy report last Friday at the oncologist's office. He was familiar, and helpful, and glad to know, as it had informed the cytologist to run a hormone test on the biopsy, which showed that it was 100% estrogen and 100% progesterone driven. He said that was rare, and asked if she took any HRT. She said yes and he said STOP IT NOW! I have been telling her for years to stop it, so there was a little laughter in the visit. He gave me a copy of the biopsy report so I am going to look up the different kinds of active carcinoma in situ it mentions, there are three. Anyway, interesting and scary and really really maddening. She will make her decisions next month regarding her course of treatment. However, I do think it will be the mastectomy. So, DES mom, 77 years old, with breast cancer, first in our family...wonder if I will be the next stat. Dang it. Stupid drug!!! Killer drug!!!

Reader in New Jersey

DES ACTION

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