THE DES ACTION VOICE
A FOCUS ON DIETHYLSTILBESTROL
Summer 2003 • #97

More Risks

By Pat Cody

"Influence of Estrogen plus Progestin on Breast Cancer and Mammography in Healthy Post-Menopausal Women," by RT Chlebowski MD et al, Journal of the American Medical Association (JAMA), June 25, 2003

"Estrogen Plus Progestin and the Incidence of Dementia and Mild Cognitive Impairment in Postmenopausal Women," by SA Shumaker PhD et al, JAMA, May 28, 2003

(Both studies are available online at www.jama.ama-assn.org)

The frontier outlook in American medicine, shoot first and ask questions later, is showing up this year in still more negative reports on HRT.

THE frontier outlook in American medicine, shoot first and ask questions later, is showing up this year in still more negative reports on HRT. (They bear out the warnings in the books reviewed in this issue – fortunately both authors also write about natural alternatives to HRT). Most of our readers are not yet postmenopausal, but many daughters tell us they are being urged to start HRT.

The Chlebowski article takes a closer look at breast cancer cases reported a year ago in data from the Women's Health Initiative (see VOICE Summer 2002), which was halted because of the data on increased risks for heart disease and cancer. They looked at breast cancer in the HRT group of 7,656 women and found 245 cases, compared with 185 cases among the 7,310 women getting the placebo. Furthermore, in the HRT group with breast cancer, 25.4% had invasive tumors compared with 16% in the placebo group. The cancers in the HRT group were more likely to be node positive and diagnosed at a significantly more advanced stage than in the placebo group. Researchers also found that abnormal mammograms were substantially higher in women in the HRT group: 35.1% compared with 21.2% in the placebo group. The report concludes:

"In summary, results from this prospective randomized trial indicate that combined estrogen plus progestin use increases the risk of incident breast cancers, which are diagnosed at a more advanced stage compared with placebo use, and substantially increases the frequency of abnormal mammograms. In light of these findings, abnormal mammograms in women receiving menopausal hormone therapy deserve heightened scrutiny. The increased frequency of abnormal mammograms requiring medical evaluation and increased breast cancer risk should be added to the already known risks of short-duration menopausal hormone use. Consideration for use of estrogen plus progestin for any duration by postmenopausal women should incorporate the current findings into established and emerging risks and benefits of these agents."

In an interview with the *New York Times* , Dr. Chlebowski said: "This will give women something to think about. Do you want to take an intervention like estrogen plus progestin that will reduce hot flashes 90 per cent, probably, at the cost of having a 1 in 25 chance of having this abnormal mammogram, which might be more significant? I think a lot of women with modest symptoms will now say, 'Wait a minute.'"

We find it disheartening that

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INSIDE

How to Join the DES Daughters Listserv

DES Daughters should check out DES-L, the DES daughters listserv 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 1,000 other DES daughters! Note: this list is operated independently from DES Action.

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Treatment for Prevention of Miscarriage

By Nora Cody

"Prevention of Recurrent Preterm Delivery by 17 Alpha-Hydroxyprogesterone Caproate," by Paul J. Meis MD et al, New England Journal of Medicine, June 12, 2003

DR. MEIS and his colleagues at 19 clinical centers in the United States conducted a study of pregnant women that began at 16-20 weeks of gestation. All of these women had a history of miscarriage. One group of 310 women received weekly injections of 17 P, a natural metabolite of progesterone, and the control group of 153 women got a placebo. They report that there was a significant drop in miscarriage risk for the progesterone group.

We note that the injections did not start until the second trimester, that is, well after the initial development of body systems in the fetus. However, we recall a report in the VOICE twenty years ago about progesterone exposure in pregnancy. It specifically warned about such treatments in the early weeks of pregnancy. So, we wrote Dr. Meis about our concern, and here is his reply:

However, we recall a report in the VOICE twenty years ago about progesterone exposure in pregnancy. It specifically warned about such treatments in the early weeks of pregnancy.

"Before starting this study, we did a thorough research of the literature concerning 17 P. The drug has been used extensively in human pregnancy and there has been no credible evidence of an increased rate of birth defects. This was born out in the results of the babies in the study. Nonetheless, we plan to do follow-up studies of the children born in the study." ■

DES ACTION TRIBUTE PROGRAM

We'd like to offer a great idea for that person who has everything: the DES Action Tribute Program. Our Tribute Program is a way for you to make your contribution in someone's honor or memory. Holiday gifts, birthdays, anniversaries, or memorial remembrances—all are appropriate occasions for a Tribute gift.

When you send your Tribute gift to DES Action, simply enclose a note indicating in whose honor and for what occasion the gift is given. Make sure to include the honoree's name and address as well as your own. We send an acknowledgment letter to you and to the honoree. The amount of the gift is not mentioned.

MORE RISKS from page 1...

the *Times* ends its story with a comment about Prempro maker Wyeth marketing a lower dose pill, and "Wyeth projects that sales of its hormone replacement products will total about $1.5 billion this year.... The company does not expect that projection to change because of the new findings."

Now to the second study listed above. In recent months we've seen media stories that taking HRT lowers the risk for Alzheimer's – surely a disease we want to avoid, especially since older women have a greater risk than men do.

It's not true.

A look at the results from the Women's Health Initiative Memory Study shows that of the 4,894 participants aged 65 or older in this study, 61 were diagnosed with probably dementia. Forty of the 61, or 66%, were in the HRT group with 21 (34%) in the placebo group. Whether this risk would be true for younger women on HRT has not been studied.

The New York Times in an interview with Dr. Shumaker wrote that: "She said that it was not known how the combination therapy might increase the risk of dementia, but one possibility was that it increased the risk of blood clots and clogged tiny blood vessels in the brain, which might injure brain cells and contribute to Alzheimer's disease and a condition called vascular dementia." ■

Book Notes

By Pat Cody

The Greatest Experiment Ever Performed on Women: Exploding the Estrogen Myth, by Barbara Seaman, 2003, $24.95, Hyperion Books.

AND explode it she does. The doctor who prescribed HRT to many of us may have been surprised by the revelation in July 2002 that HRT actually increased risks for heart disease and cancer, but Seaman was not. For years she's been warning anyone who would listen that drugs like Premarin and Prempro not only do not work– they are dangerous. She points out in the introduction that "Medical policy on estrogens has been to 'shoot first and apologize later"– to prescribe the drugs for a certain health problem and then see if there is a positive result."

Delving into the origins of Premarin, she tells us that while "Percheron stallions have the most potent estrogen in their urine of any living animal of either gender," the "collection problem" made drug researchers turn to an easier source, pregnant mares whose urine provides the estrogen for Pre(pregnant)marin (mares).

Seaman's first section on "How Did All This Happen?" is a fascinating study of the history of estrogen promotion, from DES to the pill and HRT, and the growing concern among women about the safety of these drugs. This concern led to the creation of the National Women's Health Network at the same time that the emerging women's health movement was stimulated by the publication of *Our Bodies, Our Selves* by the Boston Women's Health Collective.

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The second section "What Do We Know Now?" describes the aggressive marketing of HRT and the latest research findings on these drugs. Seaman then educates the reader in understanding some of the effects of aging on the female body. She concludes with an excellent lengthy appendix on menopause: exactly what it is, what drug treatments do, and which ones may be helpful, and a description of alternative herbs. She makes clear and concise her conclusions:

"Here is the essence of the estrogen experiment. For forty years drug companies, scientists and researchers have been playing carrot-and-stick with women's lives. They hold out poorly substantiated claims for estrogen's health benefits, which buys them time as they try to develop the proof to back up the claims. But the fact remains that after all these years, and with countless deaths attributable to estrogen via cancers, cardiovascular complications, blood clots, and other health problems, including asthma and gall bladder disease, the evidence isn't there. If the data is there, women must demand to see it before agreeing to put more pills into our bodies."

We have another worry, about which it's hard to know what to do – estrogens in our water and in the food chain. Seaman writes that a U.S. Geologic Survey in 2002

"issued the first comprehensive study of chemical contaminants in our water. Researchers examined 139 streams and rivers in thirty states and found that 40 per cent of waterways showed traces of estrogen or other reproductive hormones.... Much of this pollution can be traced straight back to animal and human waste."

We've often wondered if the estrogen and its metabolites in waste from the millions of women on the pill or HRT did in fact somehow end up in our water supply. Seaman concludes Section two with these chilling words:

"Nobody can be sure whether environmental estrogens lie behind the quadrupling of infertility rates since 1965; if

the sea of estrogens in which we live explains the fact that sperm counts are half of what they were in 1940; and if, like intersex fish and mutant frogs, male humans might begin to shed their broad shoulders and slowly morph into women. Faced with the possibility of an all-female planet, authorities might finally have to sidestep the pharmaceutical companies and take decisive action."

A Maverick of Medicine Speaks to Women: A World-Renowned Gynecologist's Solutions for a Better World in Women's Health Care, by Duane Townsend MD and Rita Elkins M.H. 2003, $19.95. Woodland Publishing, Orem UT 84097.

WE first knew of Duane Townsend as part of the original DESAD (DES – Adenosis) study financed by the National Cancer Institute starting in 1975. He was in charge of the research at the University of Southern California, one of the five medical centers making up the study group. He writes about "The DES Disaster" early in this book.

Just how much of a maverick Dr. Townsend has become since those days can be shown in these paragraphs:

"For you, the women reading this book, the effect of our present-day medical system has been nothing less than devastating. What was once a compassionate profession characterized by caring and qualified physicians has turned into a depersonalized, political empire driven by power and greed and controlled by Corporate America. Unfortunately, you have taken the brunt of this medical mania. You have suffered the abuse of a health care system that has become narrow minded, HMO manipulated and pharmaceutically dominated....

"Scores of women undergo unnecessary surgeries and take untold amounts of minimally effective prescription drugs. In addition, many doctors, because of time constraints imposed by HMOs, often skate lightly over their patients' symptoms or dismiss them altogether as psychological.... Specific alternative remedies and lifestyle changes need to be recognized as viable treatments...The sooner the medical world learns to emphasize a healthy lifestyle, proper diet and specific natural supplements over prescription medications and surgery, the sooner the absurd costs of health care will dramatically drop. Why? Because we'll all be healthier!"

Dr. Townsend details his criticisms of "HMOs and the Pharmaceutical Empire," "Women and Bias," and other challenging chapters before getting to the theme of his outlook: this is what he calls the "dynamic duo" of genistein – an isoflavone in soy that he describes as "an invaluable plant hormone that is completely at home within the human body"– and natural progesterone.

He provides many examples of conditions that have benefited greatly from his regimen, in a series of case reports. He's a big supporter of mostly vegetarian diet and exercise programs and gets into specifics in chapters on natural alternatives to HRT, hysterectomy alternative, osteoporosis, cancer and improving the odds. A separate chapter on Transfer Factor to strengthen the immune system is Dr. Townsend at his most enthusiastic and persuasive. And, while most of the book is for women, he does have a final chapter "For Men Only" advising diet changes, exercise and supplements, and comments on infertility and treating impotence.

As a reader over the years of many medical journal reports, I wish funding could be found to test Dr. Townsend's heartfelt convictions, by setting up a study with one group of women with gynecological problems getting his treatment protocol and a second"control' group with the same problems receiving current standard treatment protocols. Some studies have been done on soy isoflavones, as we report elsewhere in this issue, that cast doubt on their effectiveness. Meanwhile, VOICE readers can judge for themselves the value of Dr. Townsend's suggestions.

More information is available from his web site at www.woodlandpublishing.com

Drug Company Influence on Research Results

by Nora Cody

THE editors of the *British Medical Journal* for May 31, 2003, focused on pharmaceutical influence on physicians and on researchers, in three separate studies.

"Characteristics of General Practitioners who Frequently see Drug Industry Representatives: National Cross Sectional Study," by Chris Watkins, MD et al.

Dr. Watkins begins his article by writing that "We previously found that frequent general practitioner (GP) contact with drug industry representatives was strongly and independently associated with higher prescribing costs. This paper describes the attitudes and behaviour of general practitioners who report seeing drug representatives frequently."

Questionnaires were sent to all GPs in 200 English practices, from three groups: bottom, middle, and top fifths in prescribing costs. Responses came from 1,714 (64%) of GPs and this is what the survey found:

- Frequent contact with a drug company representative was significantly associated with a greater willingness to prescribe new drugs and to agree to patients' requests to prescribe a drug that is not clinically indicated;
- Dissatisfaction with consultations that ended in advice only;
- Receptiveness to drug ads and promotional literature from drug companies.

Frequent contact with a drug company representative was significantly associated with a greater willingness to prescribe new drugs.

The authors' comments included this conclusion:

"When new drugs became available, general practitioners who saw drug representatives at least weekly were more likely, as their first course of action, to prescribe them for a few patients and monitor the results. This conflicts with the advice given by health commissioners to use published sources of evidence such as the British National Formulary."

The second article is *"Evidence B(i)ased Medicine – Selective Reporting from Studies Sponsored by Pharmaceutical Industry: Review of Studies in New Drug Applications"* by Hans Melander et al.

These researchers looked at 42 drug company studies sent to the Swedish regulatory authority for approval in marketing drugs to treat major depression. They learned that studies receiving multiple publication, or selective publication showing significant effects of the drug, were published more often than studies with non-significant results. Their conclusion:

"Any attempt to recommend a specific selective serotonin reuptake inhibitor from the publicly available data only, is likely to be based on biased evidence."

Only recently do some medical journals require authors to state the source of funding and whether they are consultants to a sponsor.

The third article is *Pharmaceutical Industry Sponsorship and Research Outcome and Quality: Systematic Review,"* by Joel Lexchin et al.

These scientists wanted to find out if drug research paid for by the pharmaceutical industry is associated with outcomes favorable to the funder, and whether the methods of such trials differ from trials with other sources of funds. The outcome will not surprise us. Thirty studies were covered, and those paid for by the drug companies were less likely to be published. Pharmaceutical company studies were more likely to have outcomes favoring the companies. The researchers concluded that "Systematic bias favors products which are made by the company funding the research."

Only recently do some medical journals require authors to state the source of funding and whether they are consultants to a sponsor. This allows for taking that grain of salt occasionally needed. ■

On the other hand ...

By Nora Cody

MENOPAUSE magazine, published by the North American Menopause Society, recently reported on three studies showing that isoflavone supplements were ineffective in treating hot flashes.

*"Effect of Soy-derived Isoflavones on Hot Flashes, Endometrial Thickness and the Pulsatility Index of the Uterine and Cerebral Arteries""*by Penotti et al, in Fertility and Sterility 2003, vol. 79

They write that in a six-month study of 62 postmenopausal women ages 45 – 60, soy-derived isoflavones (71 mg. Daily) did no better in reducing hot flashes than did taking a placebo. Interestingly, at the end of the six months, both groups had a 40% reduction in the number of hot flashes.

"A Randomized Placebo-controlled Crossover Trial with Phytoestrogens in Treatment of Menopause in Breast Cancer Patients," in Obstetrics and Gynecology 2003, vol. 101, by Nikander et al, reports on research in Finland. They enrolled 62 postmenopausal women (mean age 54) who had been treated for breast cancer but were not taking tamoxifen. At the end of the study they learned that there was a similar drop in menopause related symptoms, including hot flashes, of around 15% in both HRT and placebo groups. When they measured only hot flashes, the placebo group actually had a greater reduction.

"Phytoestrogen Supplements for the Treatment of Hot Flashes: the Isoflavone Clover Extract (ICE) Study," JAMA 2003 vol. 290, by J.A. Tice et al.

Here the isoflavone was red clover, not soy, but the results were that they were no better than a placebo in reducing hot flashes. Two hundred fifty-two women were in this study, which gave half the group red clover in Promensil (82 mg/daily) or Rimostil (57 mg/daily), and the other half a placebo. The follow-up in 12 weeks showed little difference among the groups: they all, including the placebo group, had a reduction in hot flashes.

Looking at all three reports, we wonder – is this the power of suggestion at work? These were double-blind tests in which the women taking the isoflavones did not know whether they were getting that treatment, or a placebo, and neither did the clinic staff giving out the pills. And, unlike diagnostic tests for disease, like breast cancer, the "results" were what the women said they were, a decline in hot flashes, not a measurable effect by scientific instruments. ■

Looking at all three reports, we wonder – is this the power of suggestion at work? These were double-blind tests...the women taking the isoflavones did not know whether they were getting that treatment, or a placebo, and neither did the clinic staff giving out the pills.

Conference on Sons

AS part of the DES Update program from the Centers for Disease Control (CDC), the next teleconference will focus on Health Risks for DES Sons. This is a free informational telephone conference to present ongoing research and answer questions about potential health risks for sons. DES research expert Linda Titus-Ernstoff PhD will review research findings including a preliminary analysis of new data. Edward Messing MD, professor of urology at the University of Rochester Medical Center, will answer questions and provide an expert clinical perspective to recent research findings.

The teleconference will be on Wednesday, September 17, 8:30-9:30EST.

Registration is free and **required** to participate. You can register online at http://www.att-rsvp.com or by calling 1-877-471-4350 using Conference ID # 690030. Participants only need to supply their first name and location during registration. The deadline to register is September 15, 2003. ■

Dear Doctor

I participated in the recent CDC Update teleconference. Dr. McLachlan referred to a mouse study showing that DES exposed mice have a higher incidence of adenomyosis, a condition where uterine tissue migrates into the wall of the uterus. I have this often painful condition, which, before the advent of MRIs, was only diagnosed by a pathologist after a hysterectomy.

Can you provide us with a more detailed explanation of what seems to be a rare condition, and also let us know if there is any interest in doing a research study to see if in fact DES daughters have this condition more frequently than non-DES exposed women?

Reply from Kenneth Noller MD, Chief Investigator, Long-term Studies on DES

Adenomyosis is one of the most under-diagnosed conditions in female medicine. It is one of the causes of painful menses and causes pain when the uterus is touched. It is not at all uncommon, with estimates of prevalence as high as 10-30% of the female population. In the past it usually was diagnosed only incidentally at the time of hysterectomy, and even then, often was overlooked. More recently, MRI has been shown to be a good predictor of the disease. Unfortunately, MRI remains expensive and many areas do not have a sufficient number of scanners.

We have been recording the reports of adenomyosis among those DES-exposed women who are in the NCI-sponsored follow-up project. To date there has not been an unusually large number of cases reported to us. While that is somewhat reassuring, because the disease is so often missed, and because it is so common, it is impossible to be certain whether it is increased or not. ■

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