DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

Fall 1986 Issue #30

Victory for the Victims in New York State

By Susan P. Helmrich

On July 30, 1986, New York State Governor Mario Cuomo signed a bill into law that has a direct effect on DES exposed women in New York who have had or will have damages caused by their DES exposure.

Prior to the passage of this law, many DES daughters and other victims of toxic substances could not file law suits against the manufacturers of these harmful substances. The problem had been that New Yorkers could only sue manufacturers within three years after they had been exposed to a harmful substance or within three years after their eighteenth birthday.

For DES daughters, cancer and/or other damages often have not or will not occur until women are in their 20s and 30s. The new law changes the statute of limitations (the number of years you have to file a lawsuit) to a three year "discovery rule." Now future victims of any toxic substance have three years from the day they discover their illness to file law suits against the manufacturers. The new law also allows for a one year "revival period" for victims of DES, asbestos, polyvinyl chloride, chlordane, and tungsten carbide who had previously been barred from the courts in New York.

It took six years for this bill to be passed by the New York legislature. Initially, a small group of DES daughters who had had cancer went to Albany with the hopes of changing the statute of limitations so that they could sue the manufacturers of DES, as Joyce Bichler had done in 1979. I was among this group of daughters who made frequent trips to Albany each spring, hoping to obtain justice. But before the New York State Senate could be convinced that we should be allowed access to the courts (the Assembly passed the bill each year), we had to educate them — one by one — about DES.

Lobbying Takes Years

Lobbying meant writing letters and sending packets of information containing scientific literature and other written material about our issue. We went door to door, office to office telling our stories. Lobbying meant talking to complete strangers about our experiences of having cancer, how we would never be able to have our own children, and how we had had our vaginas removed. I learned how to tell my story in front of T.V. cameras and newspaper reporters. It wasn't easy, but it was the only way we would win the battle against the mighty New York State Senate.

During the next few years, we gained the support of DES Action, the New York Public Interest Research Group (NYPIRG, the state affiliate of Nader's Public Citizen), the AFL-CIO, and other victims and their families. Each year powerful forces in the State Senate opposed the bill. Obstacle after obstacle was raised — collateral estoppel, joint and several liability, periodic payments, caps on pain and suffering, insurance premiums, medical malpractice, etc., etc. Six years ago these words meant nothing to me — they soon became part of my daily vocabulary. During the six years of extensive lobbying, the DES daughters, the other victims, and concerned groups had to counter each obstacle and convince the Senators of their rights.

continued on page 6

Inside

Editorial ..... p. 2
The First Hurdle was Conception ..... p. 3
Premature Labor Handbook ..... p. 5
Letters ..... p. 7

Get Into the 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 around 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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Editorial

We are inspired by Susan Helmrich's account of work on getting the statute of limitations changed in New York (see page 1). Her words, "Perseverance does pay off. If you believe in something enough and don't give up on the cause, you can help to create change" sums up the DES Action philosophy. Consumers often are told that "it's the law" or "the statute in this state means you can't sue" as though these laws and statutes were engraved in stone and cannot be changed. The hard work and skill of DES Action and New York PIRG show that we can get justice. They also show that the insurance companies and manufacturers who were our opponents on this issue can be defeated. These same forces are also our opponents in many states in trying to get what they call "tort reform" — in fact, attempts to limit our access to the courts. That too can be defeated.

If you seek compensation for DES-related injuries and "the statute" stands in your way, talk with other consumer groups, such as those for asbestos workers, about the need for a new statute in your state. If your state laws *do* give consumers their day in court, and you contemplate a suit, it's a good idea to see a lawyer now to determine your filing deadline. Product liability cases are taken on a contingency basis — the attorneys are paid only if you win. So, seeing a lawyer will not cost you anything now, and it could mean that you can "take them to court." ■

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Personal Story

The First Hurdle Was Conception ...

By Judy Turiel

Seven years separated our first pregnancy from our last. The first ended unhappily, after 5½ months of routine obstetric care and routine daily activities. The baby was rushed from delivery to the Newborn Intensive Care Unit, where the latest medical technology kept him alive for a fraction of a day. Our last pregnancy ended with joy and relief — a healthy baby just 2½ weeks early.

The years between these two pregnancies were stretched by hesitations over the likelihood of another preterm delivery, and the real possibility of a premature baby with serious, lifelong health problems. Our decision about attempting another pregnancy was compounded by my need for infertility treatment.

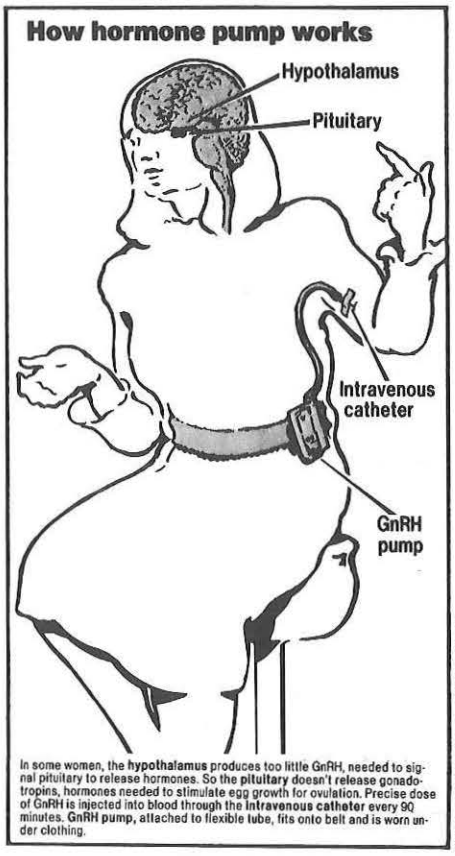
The years were also marked by changes in pregnancy-related health care and by changes in me as a health care consumer. Gradually, I informed myself about success rates of various preterm labor treatments and known risks for me and for the baby. I became more assertive about selecting health care providers with expertise necessary for my particular situation and openness to discussing all aspects of my care. What I learned, by the time our son was born, may be of use to other DES daughters facing similar decisions.

The first hurdle was conception. Since I do not ovulate on my own, my first pregnancy occurred after taking Clomid, a medication that stimulates ovulation in some women. Although Clomid is used quite commonly now for a range of infertility problems (including "unexplained" infertility, and as part of *in vitro* fertilization procedures), researchers are not certain how Clomid works. The pregnancy rate appears to be lower than expected, given the rate of ovulation obtained with Clomid. There can be unpleasant side effects, and Clomid can reduce the quality of cervical mucus thus reducing the chance of pregnancy. In addition, questions have been raised about the possibility of effects on the fetus, though evidence only comes from animal studies.

Seven years later, a new technique for stimulating ovulation was appropriate in my case — an intravenous pump that injects a hormone called gonadotropin releasing hormone (GnRH) at 90 minute intervals for approximately two weeks prior to the desired ovulation. It is this regular, pulse-like hormonal message — from the brain's hypothalamus to the pituitary gland — that is lacking in my own body. This initial step, provided by the pump, sets in motion a cascade of further hormonal activity that results in maturation of an egg, ovulation, and the possibility of conception. The pump itself fit on a belt, or inside my pants pocket, with the intravenous line running under my blouse into my arm. Only I could hear a slight buzz each 90 minutes, as the pump released its dose of GnRH.

During experimental trials, the ovulation pump has most successfully led to ovulation and pregnancy in women with a diagnosis of "hypothalmic anovulation," or amenorrhea (see drawing). Researchers have had less success using the pump in cases of polycystic ovarian syndrome. Although more complicated and expensive than taking Clomid pills, the process is more "physiologic" — that is, it more closely mimics a natural menstrual cycle, using a hormone the body normally produces, in the normal pattern. Known side effects involve the mechanics of this process, such as infection or bruising where the IV tube is inserted. The significant risk of multiple births attached to some fertility treatments (for example, use of the hormone Pergonal) does not arise with the GnRH pump.

The pump is now available at many university medical centers. As this treatment is still new, centers differ in how they use the pump, as they search for the technique with greatest success and least side effects. One variation, for example, is to place the catheter under the skin instead of into a vein. Pros and cons of a particular method should be discussed with physicians who have experience with the GnRH pump.



San Francisco Examiner

Most women who become pregnant using the pump do so within three months. My husband and I were excited, of course, at news of my positive pregnancy test the second month. Yet we knew our work had just begun. The next major task was to prolong this pregnancy long enough to have a healthy baby.

An obvious difference this time was that I knew I had a high risk of going into labor well before term. Medical studies had now established that pregnant DES daughters do deliver pre-

continued on page 4

Conception continued . . .

maturely more often than do non-exposed women. Furthermore, any woman with a previous preterm delivery is at risk for another. This knowledge allowed me to prepare for a difficult pregnancy. In addition, a new approach to obstetric care was developing among some practitioners: Educating high risk women about early signs of preterm labor, so they can help catch problems early. Unlike my experience with my first pregnancy, I would now be taught what warnings signs to look for, and what preterm labor contractions feel like. At last, some medical professionals were taking seriously the idea of active involvement by patients.

Before attempting this pregnancy, I had consulted with an obstetrician whose specialty in preventing preterm births relies heavily on this new approach. We had discussed his estimate of my chances for a successful pregnancy, as well as the options for treating preterm labor should it occur. I knew that bedrest would likely be necessary, and so resigned myself to weeks or even months of an immobile, horizontal life. I had learned all I could about the medications used to stop excessive contractions (most commonly, terbutaline or ritodrine — see box). Although keenly aware that unknown long-term effects on the baby might someday be identified, my husband and I decided the known risks of taking these drugs were acceptable in trying to avoid the known health dangers for babies born very prematurely.

In addition, my obstetrician was working with a new device that could improve my chances for prolonging the pregnancy — a portable, home-monitor that detects uterine contractions and can help catch preterm labor in its early stages, when medical treatment is most likely to be successful in stopping it. The monitor measures changes in pressure against a disc, emitting *no* radiation or ultrasonic waves. Once I had completed the first half of my pregnancy, I spent at least two hours each day with the small monitor strapped around my belly. A record of contractions, stored inside the monitor, was transmitted over the telephone to trained nurses, who informed my obstetrician of any unusual uterine activity. On the day they saw what they called "a significant increase in contractions . . . more than should appear at this point in pregnancy," I went to the hospital to be examined. Based upon the contractions *and* changes in my cervix, a diagnosis of early preterm labor was made. My regimen of bedrest and medications began.

With the exception of a three week hospital stay, I spent most of the next four months at home in bed or on a couch. An obstetric nurse-practitioner made regular "house-calls." Information from the home-monitor helped determine whether I needed a change in medication dosage, and whether I should be examined for further cervical changes. Without this daily record of uterine activity, I might well have spent a considerably longer time in the hospital in order to prevent a preterm delivery. Or, I might have delivered far too early. As with any medical device or procedure, the value of home uterine monitors must be established through well-designed studies. Preliminary reports indicate that home-monitoring can help identify women with excessive contractions and contribute to decisions about treatment. Similar uterine monitors are available in various parts of the country, where private companies have enlisted the participation of local physicians.

The monitor itself, of course, is only a tool. The information it provides must be interpreted by knowledgeable nurses and doctors, who are following closely the individual woman's pregnancy. Uterine contractions are only one sign that preterm labor may be developing; in order to avoid overtreatment, other indications — such as cervical change — must be observed. Most important, then, is the commitment, vigilance and accessibility of experienced practitioners who are using the home-monitor as one dimension of a woman's prenatal care.

As a DES daughter, my decision to attempt a pregnancy that would almost certainly require intervention with medications, as well as ultrasound, was not an easy one. We know too well that the "latest medical advance" can bring more harm than good. As a person who clings to her manual typewriter in the face of those powered by electricity (not to mention word-processors), I was not eager for a "high-tech" pregnancy. My husband and I considered long and hard our options; we came close to choosing not to take the risks of trying again to become pregnant, and deciding to continue our child-free way of life.

We decided on one more try only after evaluating the best information we could obtain about current treatments and identifying questions that cannot yet be answered, such as the

continued on page 6

A group of drugs called "tocolytics" (labor-inhibitors) are currently the most prominent medications used in attempting to stop premature labor. Of all people, DES daughters recognize the need to be cautious about medications during pregnancy. However, knowledge and practice are continually changing, and there is much that is simply unknown about effects of these medications on the mother or child.

The uterus is composed of "smooth" muscle that contracts and relaxes involuntarily. Tocolytic drugs (*ritodrine* and *terbutaline* are the most commonly used) stop contractions of premature labor by relaxing the body's smooth muscles — including the uterus. Unfortunately, these medications also affect smooth muscles in other organs, causing undesirable side-effects. These side-effects are the risks which must be weighed against the drug's benefits. The most pronounced known physiological side-effect is a considerable increase in the mother's heart rate and a possible decrease in blood pressure. ■

Book Review

The Premature Labor Handbook

Reviewed by Judy Turiel

The Premature Labor Handbook, by Patricia Anne Robertson, M.D. and Peggy Henning Berlin, Ph.D. (Doubleday) 1986, 218 pages. Paperback. $9.95.

My mother was prescribed two main treatments to avoid miscarrying me: DES and bedrest. Perhaps bedrest helped, as we now know the DES did not. Fortunately, DES is no longer prescribed during pregnancy in this country, so I was spared that treatment during my own pregnancy. I was not spared bedrest, however, which may be making a comeback. For some pregnancy problems, inactivity and/or less downward pressure may buy crucial extra time for the unborn baby.

"Bedrest" comes in a variety of forms. My mother could sit up in bed; I could not. I was able to use the bathroom; some women are restricted to bedpans. In my mother's day, there were no books to help people cope with spending several weeks or months of a pregnancy "on bedrest." Today, *The Premature Labor Handbook*, by Patricia Anne Robertson, M.D. and Peggy Henning Berlin, Ph.D., attempts to help pregnant women and family members cope with physical and emotional aspects of this experience.

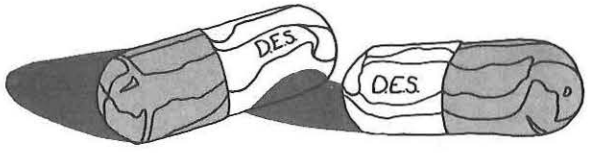
The book contains sections on medical aspects of premature labor and weakened or "incompetent" cervix (including definitions, diagnosis and treatment of these conditions), and on "the hospital experience," during preterm labor, childbirth preparation, nutrition and exercise for women on bedrest, the preterm delivery and premature baby. In addition, there are sections on the emotional stresses of premature labor, on relationships with other adults and with other children, on "maximizing time and space," and on "embracing the challenge" of premature labor. One chapter is directed to the family of the pregnant woman. Finally, there is a glossary of medical terms and of various medical procedures.

I read this book shortly after spending the last four months of a pregnancy in bed. Unfortunately, I hesitate to recommend it to women on bedrest, or to those who may someday find themselves in that position. Two related characteristics seriously undermine this potentially valuable, and certainly needed, handbook about high risk pregnancy. One is the style and language. The book is written in heavy "social science-ese." For example, the pregnant woman is advised to let her spouse do most of the "interfacing" with her inlaws. Discussion of "time-abundance" seems a convoluted way of suggesting activities to fill the days. If you are a graduate student in sociology, perhaps the lumbering sentences and unnecessary abstractions will be manageable; however, if you want straightforward information and accessible ideas, this book may not appeal.

The second, more serious problem is the book's psychological orientation. Although it may be important for couples to understand their feelings about and reactions to their high risk pregnancy, this book goes overboard in seeking underlying psychological explanations of various reactions. When a long awaited television show is pre-empted, for example, one need not look for hidden unconscious feelings to explain a bit of anger. You're bored, and you were counting on those two hours of mindless entertainment. Nor was I taken with gimmicks for "re-directing energy" or "embracing the challenge" — one of those life-challenges we would all prefer to miss. Of course, you try to make the best of a bad situation, and if some personal insights arise from the experience, that is well and good.

My impression is that a well-meaning obstetrician was hijacked by psychologists. It's too bad, because the book does contain useful, concrete suggestions and basic medical information. (One qualm I have about some of the medical discussion is that the reader does not get a good sense of what information is adequately established — that is, there are good research studies, involving humans as well as animals — and what is mere belief or theory currently popular among the medical community.) The book's important message — that women must be educated about their pregnancy, participate actively in detecting early signs of preterm labor, be assertive about calling their practitioner *whenever* a problem is suspected — is buried within a psychological framework that is at the least distracting and, for some women, may even be debilitating.

My final conclusion about this book: If you have the patience to skim over wordy, superfluous paragraphs, and take parts of the book with a large grain of salt (this is not nutritional advice), you may well find helpful suggestions and information. And anyway, it's not a bad way to kill a few hours while confined to bed. ■



Victory continued . . .

Perseverance Pays Off

Finally, this year, the bill passed both houses and was signed into law by the Governor.

It was a long battle. As a lobbyist I learned a great deal about tort law, politics, and how "the system" works. We were often in situations in which we met face to face with the professional lobbyists from the drug companies and other major opposition groups (especially insurance companies and big businesses). We learned that as difficult as the process was, the system does, in fact, work. Perseverance does pay off. If you believe in something enough and don't give up on the cause, you can help to create change.

The bill signing ceremony was truly a moving experience, marking the culmination of many years of hard work by many people. Joyce Bichler, Debbie Meisenberg, Jane Dolan, Sybil Shainwald, Gerry Scher, and many other DES mothers, daughters and their families were there to witness Governor Cuomo sign the bill into law. There were many speakers — Senators, Assemblymen, the Attorney General. In addition to two other victims (an asbestos widow and a man suffering from "heavy-metal disease"), I was given 90 seconds to speak. I spoke on behalf of all DES daughters and their families in thanking everyone who had helped to make the law possible.

Key Points

The key points of the bill are described below. If you are an exposed DES daughter or son and if you feel you have a legitimate case (that is, damages for which you feel you should be compensated) in New York State, we urge you to consult an attorney immediately. Also, if you know anyone who falls into this category, please let them know about the new New York law. You will have until July 30, 1987 to file a suit.

The two key points of the bill are as follows:

1. *A one-year revival period for present victims injured by DES, asbestos, tungsten carbide, polyvinyl chloride, or chlordane.*

If you discovered your illness or injury from DES or other substances prior to July 1, 1986, and have previously been unable to file a case in New York state because of the statute of limitations, you now have *one year* (until July 30, 1987) to file a lawsuit. This bill does not mean that you will automatically receive compensation. It does mean that those victims who were previously barred from court can now file their cases and proceed through the judicial system.

2. *A three-year discovery rule for future victims of any toxic substance (including DES).*

It is still unclear how this part of the law will be interpreted by the courts in DES cases. The three-year rule may be applied to the time you first discover your DES exposure, or to when you first discover any injury from DES exposure. In order to preserve your rights to sue, you should immediately discuss any concerns regarding DES related injuries with an attorney familiar with DES litigation.

The bill is complicated and we are not in a position to make legal interpretations of the new law in New York State. We do urge you to seek legal advice from a competent attorney, one who has both experience and expertise in this area of law. ■

For more information about the New York State bill, or for listings of competent attorneys in DES litigations, contact:
DES Action
Long Island Jewish
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New Hyde Park, NY 11040
(516) 775-3450 (Tuesdays and Thursdays, 9 am - 2 pm)
or
NYPIRG
9 Murray Street
New York, NY 10007
(212) 349-6460

Conception continued . . .

longterm effects of current prenatal medications on the child. It is these unknowns that pose troublesome dilemmas for those of us who require new reproductive technologies in order to bear a child. Our healthy skepticism of medical claims lingers through any decision to seek the benefits and accept the risks of medical intervention.

And there are political dilemmas: We are concerned that the expense of new technologies makes them accessible to only a small percentage of people who could benefit from them, and that money is less available to support basic health care needs of the wider population. We are concerned that as medicine becomes increasingly technological, the patient/consumer will be less able to participate in health care decisions.

All of these concerns about the direction health care is taking were in conflict with our individual desires to try once more to have a child. Faced with difficult personal decisions, however, the only option for health care consumers is to insist on straightforward, thorough information about the particular medications, surgery, or technologies available to them, and to work actively toward increasing medical knowledge and improving the choices that knowledge shapes.

Information about the monitor I used, called "Term Gard," can be obtained from Tokos Medical Corporation: 1-800-248-6567 (in Calif., 1-800-258-6567).

More information about the procedures described here is available in the following articles:

E. Schriock and R. Jaffe, "Induction of Ovulation with Gonadotropin-releasing Hormone," Obstetrical and Gynecological Survey, Vol. 41 (July, 1986), pp. 414-423.

M. Katz, P. Gill and R. Newman, "Detection of Preterm Labor by Ambulatory Monitoring of Uterine Activity for the Management of Oral Tocolysis," American Journal of Obstetrics and Gynecology, vol. 154 (June, 1986), pp. 1253-1256.

If you have trouble locating these articles, contact DES Action. ■

Letters to the Editor

DES Guide Helps!

Dear Editor,

Thanks to your special DES guide, I was able to make it thru my pregnancy and gave birth to a healthy *full-term* baby girl on 1/29/86, even though I have a T-shaped uterus. I was on terbutaline for 1 1/2 months and a day after I went off it, D was born. I also had a wonderful doctor. So, thanks again. I wish I could give more at this time, but being out of work for 5 months, I'm a little low.

Thanks again!

C.H.
Arcata, California

Insurance Victory

Dear Editor,

I want to share with you how I finally got my insurance company to pay for my DES exams.

Here's the history of my claim with my insurer (Atlanta Insurance Company). Five months after I sent them a claim, I received a letter from them stating that DES exposure is a preexisting condition not covered by my student policy at California State University. My gynecologist wrote the company and explained the California law which states that DES patients have medical coverage without exception. When I called the company to follow-up, I was told their insurance only covers diagnosed illness, not check-ups such as those to screen DES exposure.

After consulting with DES Action, I sent the insurance company a copy of the California law, and told them that if I did not hear from them soon, I would write every university that carried their insurance and inform them of the company's failure to pay on this type of claim. I also said that I would write health centers and newspapers as well.

A short time later I received a check covering all but $15 of my original claim.

I now subscribe to a different insurance company's policy. And I have sent a copy of the California law to the Health Center at my branch of California State University.

Thanks for all your advice in helping me deal with this issue.

Sincerely,
D.G.
California

(**Editor's note:** Several states have now passed legislation similar to California's, prohibiting insurance companies from discriminating against DES-exposed clients. These states are: Florida, Illinois, Maine, Maryland, Massachusetts, Minnesota, New York, Ohio. If there is no such law in your state, contact your DES Action office to work with them in getting such a law passed.)

DES Action Cares

Dear Editor,

This past week I had one of the most unique and rewarding experiences of my life. I am the mother of a daughter who had clear cell carcinoma of the vagina in the fall of 1984. Last Wednesday I attended my first meeting of the San Diego chapter of DES Action. . . . I was the only DES mother at this particular meeting. I can hardly describe the feeling of support I received from (DES Action) members. Please believe me when I say that I will never forget meeting these exceptional young women for the first time.

To those of you who have been hesitant or afraid to attend a meeting in your area — put those feelings aside. These are *not* depressing, grim meetings. They are upbeat, constructive, caring, and sharing. You'll meet some wonderful people who know and understand what you and your family have been through. They can and want to help you.

Sincerely,
Y.S.
California

For Your Information

Despite the fact that the Food and Drug Administration (FDA) has approved the use of estrogens (including DES) for osteoporosis, consumers should be aware of the qualifications and unknowns about this use that the FDA presents in the following excerpt from the Journal of the American Medical Association *for June 13, 1986. You may want to go over these points with your doctor as you weigh the risks and benefits of taking estrogens.*

Osteoporosis Added to Labeled Indications for Oral Estrogens: The FDA has determined that osteoporosis in post-menopausal women can be added to the list of approved indications on the professional and patient labeling of short-acting oral estrogens, including conjugated estrogens, diethylstilbestrol, esterified estrogens, estradiol, ethinyl estradiol, estropipate, and stilbestrol. The labeling change does not apply to estrogen products used in contraception. The recommended daily dosage of short-acting oral estrogens in osteoporosis is an amount equivalent to 0.625 mg of conjugated estrogens administered for 21 days in 28-day cycles. Manufacturers may add the following to the indications section of professional labeling of short-acting oral estrogens:

"(Drug name) is indicated in postmenopausal women *with evidence of loss or deficiency of bone mass, to retard further bone loss* and estrogen-deficiency induced osteoporosis. The product should be used with other important measures such as diet, calcium, and physiotherapy. A more favorable benefit/risk ratio exists in a woman who has had a hysterectomy because she has no risk of endometrial carcinoma (see boxed warning).

"There is evidence that bone loss is increased in many women following the menopause, but there is no clear way to identify those women who will develop osteoporotic fractures. There is also evidence that the rate of bone loss can be reduced in postmenopausal women by taking estrogens, but *substantial evidence is lacking that estrogens decrease the incidence of osteoporotic bone fractures.* Women who have had an early surgical menopause (oophorectomy) appear to be at increased risk for the development of osteoporosis." (italics added)

— by Stuart L. Nightingale, MD
Associate Commissioner for Health Affairs
Food and Drug Administration

DES Action USA

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