

# THE DES ACTION VOICE

A FOCUS ON DIETHYLSTILBESTROL

Fall 1992

#54

## Menopause and After

by Pat Cody

**A**s DES daughters move toward their 40s, often their thoughts—and questions—turn to menopause. Will it be different for them than for non-exposed women? Is taking HRT (Hormone Replacement Treatment) a good idea when DES exposed women have been advised to limit their use of estrogen? These are also questions facing younger daughters who have had a surgical menopause, and we have had numerous articles and letters in the **Voice** over the years on these issues. We have no answers to these questions because of the lack of research in this area. We have recommended that the National Institutes of Health and DES researchers study the impact of HRT on DES daughters and mothers.

DES daughters are part of the baby boom generation, and there is a large group in the population with concern about menopause. According to *New York Newsday*,

*"There is no consensus within the medical community about even the definition of the menopause, let alone the risks and benefits associated with hormone therapy..."*

"within five years an unprecedented 35 million women—the older female members of the Baby Boom—will enter menopause..." That explains the number of new books on this topic. Here is my description and comment on some of them, but first I want to mention something of particular interest to us that is not covered in these books. Some of them refer to estrogen creams used to alleviate vaginal dryness. We know from letters we've had that one of these creams, Ortho Dienestrol, contains Dienestrol, which is on our list of DES medications. No studies have been done on whether this is safe for a DES-exposed woman to use.

**The Menopause, Hormone Therapy, and Women's Health—Background Paper,** Office of Technology Assessment, May 1992. \$6.00. Order from New Orders, Supt. of Documents, Box 371954, Pitts-

burgh, PA 15250-7954.

An exceptionally fine report, well presented with charts and graphs, covering the entire topic and ending each chapter with scores of references. The chapter on "Understanding the Menopause" includes information on historical, social and cultural perspectives; biology and symptomology; long-term consequences of changes in ovarian hormone levels. Chapter 3 on "Treatment of Menopausal Symptoms and Prevention of Future Disease" covers estrogen and combined hormone therapy, cancer risks of that treatment, and alternative treatments. "Hormone Products and Prescription" is a separate chapter on labeling, generics, prescribing practices, and promotion of hormone therapy. "Current Research and Future Needs" covers the current state of research as well as topics that will fill the research gaps. "Conclusions" discusses the relation between menopause and diseases of aging, the need for clinical trials, refining estimates of risks/benefits from hormones, investigating alternatives to hormones. Among the last words in this book:

"Many studies have shown that women feel disenfranchised from the health care system and contend that providers do not listen to them. They also report

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INSIDE

**Our  
Bill  
Passed!**

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## 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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## ✍ letters to the editor

Dear Editor:

My daughter Rose was born eight weeks premature and has brain damage. She has cerebral palsy, severe developmental delays, a seizure disorder, and is visually impaired. I feel sure that Rose's problems are related to the fact that I am a DES daughter.

I would like to share information and network with other families who have an injured 3rd-generation child. My hope is that we can collect enough information about injured 3rd-generation children to make people aware of a continuing DES tragedy that has so far been denied by the medical community. You can write to me at:

DES Third Generation  
Network  
Box 328  
Mahwah, NJ 07430  
—Elizabeth Wandelmaier

Dear Editor:

I am writing to thank DES Action for its continued efforts on behalf of DES exposed mothers, daughters and sons. I credit the organization with saving my life ten years ago.

Ten years ago when I was 22 years old, I was experiencing bleeding between periods. Visits to three gynecologists proved unfruitful as they were puzzled by my symptom and continued to schedule appointments to monitor my condition. I happened to be shopping at a local mall where there was a women's health van offering free women's health information. In the van was a DES Action brochure, "If You Were Born Between 1941 and 1971" which I read and took

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## Notes From Nora

### A Bill to Aid DES-Exposed People Has Now Been Passed by Both the Houses of Congress, and White House Approval is Expected!

**A**s of this writing, federal DES legislation is just one signature (President Bush's) away from becoming law! The Bush Administration has already indicated their support for this legislation. All of you and all DES-exposed people and their families and friends share in this historic victory.

In addition to the DES bill's passage, we also await approval of the Congressional NIH Appropriations bill, which provides the actual funds to carry out our program of DES research and education. On Monday, September 14, the Senate Appropriations Committee allocated \$1.5 million in fiscal 1993 (Oct. 1-Sept. 30) for the first year of the DES education and research program. **This is the first time the U.S. Congress has ever recognized and allocated funds for the needs of DES-exposed people.** Here is the Committee's statement on DES:

"The Committee continues to be very concerned about the level of attention devoted to studying the impact of the synthetic



*Nora Cody, DES Action, and Margaret Lee Braun, DES Cancer Network, present a plaque to Rep. Louise Slaughter.*

estrogen, diethylstilbestrol (DES), which was prescribed to some five million American women from 1941 to 1971. DES, which was prescribed to reduce the risk of miscarriage, has been linked to increased incidence of cancer, infertility, miscarriages, and other health problems in the women who took the drug, their children, and their grandchildren.

"The Committee has included sufficient additional funds in order to assure prompt implementation of the DES Education and Research Amendments of 1992 expected to be approved this year. An additional \$1,500,000 has been included above the amount requested in order to begin funding the national education program and longitudinal studies mandated in the legislation. As required by the legislation, the Committee expects that the institutes will work closely with organizations representing those effected (sic) by DES in developing and imple-

menting the national education program.

"The Committee was pleased that the NCI joined with the Office of Research on Women's Health and several other institutes this April in convening a research conference on DES. The Committee strongly encourages NCI and the other involved institutes to undertake efforts to implement the recommendations stemming from this conference. The Committee asks that it be provided with a report outlining the steps undertaken and planned to carry out the recommendations of this conference prior to submission of the fiscal year 1994 budget request."

The \$1.5 million appropriated for 1993 is just for the first year of a three-year program. We will need to return to the appropriations committee next year and the following year to ask for re-funding of the DES program.

*Note: we originally asked for*  
*continued on page 4*



**NOTES from page 3...**

\$2 million for the entire three years, and then amended that amount to request closer to \$6 million. Thus, we are very pleased with the \$1.5 million allocation. Many bills become law but never receive any appropriation, and thus are not implemented. With this appropriation, we know that federally-funded DES education and research will at last become a reality!

As I have often noted, the outpouring of eloquent and moving letters to members of Congress was the key factor in moving this legislation forward—in record time. My thanks to each one of you who wrote to your representatives. And our heartfelt thanks to Representative Louise Slaughter and Senator Tom Harkin and their extremely helpful and dedicated staffs.



On August 6 members of DES Action and the DES Cancer

Network met with Dr. Vivian Pinn, Director of the NIH's Office of Research on Women's Health, and other NIH officials, to discuss the current status and future plans for DES research. We were encouraged by the NIH representative's expressions of strong commitment to DES research. Here are some of the highlights from that meeting:

☛ The report from the April NIH Conference on DES Research is in "final first draft" form and will be available sometime this fall. Anyone interested in obtaining a copy can write to: Dr. Ruthann Giusti, NCI, Bldg. 31, Rm. 3A44, Bethesda, MD 20892.

☛ Some of the institutes of the NIH are beginning to implement recommendations from the conference. The National Institute of Environmental Health Sciences has obtained tissue blocks to attempt to trace the "molecular biomarkers" for clear cell cancer (i.e. to try to

***With this appropriation, we know that federally-funded DES education and research will at last become a reality!***

ascertain why some women get this cancer and others don't). They have also established a lab at neighboring Duke University and are studying the effects of DES exposure on bones. They have also begun studies on DES sons and are completing a survey on the reproductive health of DES sons.

☛ The National Cancer Institute is collaborating with the American College of Ob/Gyns to develop technical guidelines to distribute to their membership on recommendations for screening, ob care, and treatment for clear cell adenocarcinoma. They hope to include these guidelines on the board exams (which means those entering ob/gyn practice must study the recommendations). NCI is also working through their Gynecologic Oncology Group on a proposal to incorporate "stage three" clear cell cancer patients into treatment trials for new drugs.

We are sharing our ideas about research and education with the NIH, and plan to meet again in early November to continue our collaboration. The DES Action Voice will report on the ongoing research projects as they yield results.

**LETTERS from page 2...**

home. I asked my mother if she had taken DES while pregnant with me. After a little reading and talking, she recognized the word stilbestrol as the medication she was given during the 2nd-8th months of pregnancy.

With this information in hand, I contacted a local hospital which had a DES screening clinic. I was given an appointment immediately and I was diagnosed with vaginal clear cell adenocarcinoma. I was operated on within days and had my vagina, uterus, Fallopian tubes, and one ovary removed. Six weeks later I received 35 radiation treatments.

I credit DES Action with

saving my life. Getting to the DES clinic and getting treatment may not have happened without the grass roots efforts of this volunteer organization. I want you all to know that your efforts are very meaningful to your members and to the vast majority of the general public who seem to have the basic DES information.

Keep up the good work!

Reader



# Day or Decade: The Dutch DES Court Case

by Ellen t'Hoen

**T**he history of the Dutch DES law suit goes back to 1984 when a group of DES cancer daughters decided that the time had come to consider product liability claims against the manufacturers of DES. After fruitless attempts to persuade the companies to offer a settlement, the six women started a liability suit against Dutch companies in 1986. DES had been marketed in The Netherlands by over 20 different companies, 10 of which had DES on the market in the years the six DES daughters were born.

Both the Amsterdam District Court in 1988 and the Court of Appeals in 1990 ruled that the 10 manufacturers could not be held liable because there was a possibility that others had made DES as well. The daughters had to prove that the drug taken by their mothers had come from one of the 10 defendant companies. The procedure got stranded on legal obstacles.

The most important problem is that neither the women nor their mothers know the makers of the pills or injections that were taken. Therefore, the basis for liability in this case is taken from the concept of joint liability. Under Dutch law it is possible to hold several parties liable for the consequences of an event, if one of them must have caused the event but it is not possible to point out which individual did it. A rather famous example is the case of the two hunters who both shot at a bush behind which an ignorant camper was eating his sandwich. The camper got hurt but it was not possible to determine whose shot

*"Great injustice would be done to the DES daughters if the legal system could not find another basis for liability, and find a solution."*

it was that caused the wound. In such cases the Dutch law offers the possibility of joint liability. The two hunters are each liable for the damage caused by their careless behavior even though only one of them actually hurt the camper.

The question of whether this principle could be applied in the DES case became the central theme of the proceedings. According to the courts' reasoning, all the companies who brought DES on the market should have been sued; it had to be an inclusive group. This brings the DES daughters to an impossible position with an unfair burden of proof. It is practically impossible to ensure that the entire group of manufacturers is known, and on top of that, the defendant companies have a very easy defense: without having to prove it, they can just say, "there may have been more." How can the daughters argue against that: how do you prove that something has not happened?

## Advice to the court

After the Court of Appeals ruling, the DES daughters appealed to the last possible place and took the case to the Hoge

Raad, the highest court in the Netherlands. The decision is scheduled for October 9.

In cases of legal principle, the court is given advice by the Public Office. The Advocaat-Generaal gave his conclusion in a 30-page document this past June.

He concluded that the decisions of the previous courts should be overruled. He agreed with the statement that the joint liability articles in the civil code are not written for cases like this. However, he acknowledged that great injustice would be done to the DES daughters if the legal system could not find another basis for liability, and find a solution. The Advocaat Generaal suggested, to the great surprise of many people, not least the lawyers in the Netherlands, the introduction of the market share liability as a basis for damage payment by the companies. This is a unique and rather radical opinion. Many legal specialists in the past have considered the market share liability an American novelty, not appropriate for the Dutch situation.

Now many women are anxiously waiting for the court's ruling. Even if it is positive, the procedure will not be over. Then the questions of negligence, foreseeability and causation will be raised and dealt with by a district court. Technically it is possible that after October 9 another round of many years of court procedures will start. "American DES daughters have their day in court, we have our decade," said Wanda de Wit of the Dutch DES Cancer Network.

**MENOPAUSE** from page 1... having inadequate information on which to base a decision concerning hormone therapy. Patients and health care professionals alike tend to know relatively little about the menopause and about the risks of conditions that may be associated with it. There is no consensus within the medical community about even the definition of the menopause, let alone the risks and benefits associated with hormone therapy, and there is little information about a woman's natural progression through the menopause and the years that follow. Moreover, there is no agreement on what constitutes a 'normal' menopause and few conclusive research findings on the normal hormonal changes associated with aging."

You can do your community a favor by asking your library to get this book. It's not published in a way that would get a review in the *Library Journal*, so librarians may not know about it.

**Natural Menopause: The Complete Guide to a Woman's Most Misunderstood Passage**, by Susan Perry and Katherine O'Hanlan M.D., Addison-Wesley, 1992, \$19.95.

"Menopause is not an illness with symptoms. Rather, it is a natural process with certain signs of its approach."

This book sets out to answer most of the questions women have about menopause, and succeeds in covering a lot of material in a very readable style. The authors devote nearly 40 pages to "The Great Hormone Debate" and emphasize what a slow, careful and individual decision this is. They write on "Measuring your moods at meno-

pause" and "How menopause will affect your sexuality," and a good 20 pages on "Understanding osteoporosis."

The final section is on "Taking Charge: Eating Well, Exercising, Skin Care." Most readers will be cheered by these sentences:

"Exercise's ability to slow down the aging process can not be overstated. Study after study has shown that many of the physical and mental changes we associate with aging—and with menopause—are really the result of inactivity."

**The Silent Passage: Menopause**, by Gail Sheehy, 1992, Random House, \$16.00.

Sheehy has written an easy-reading book inspired by her own entry into this stage of life. The titles of the four sections show her approach: "The Need to Know and the Fear of Knowing," "The Perimenopause Panic," "The Menopause Gateway," and "Coalescence." She makes a clear presentation of the risks and benefits of hormone treatments and comes down on the side of a cautious use of hormones, pointing out that "A woman's chance of dying from heart disease is more than double that of dying from cancer of any kind....cardiovascular disease quietly kills off one in two women over the age of fifty."

However, she does raise concerns about the progestin in the combined estrogen-progesterone treatment:

"As for the safety of progestins, what I found out was that Provera has never been approved for treatment of menopause by the Food and Drug Administration. In fact, the FDA's Advisory Committee on Fertility and

Maternal Health Drugs acknowledged that the progestins approved for hormone replacement therapy are "none." Government health officials were asked at an FDA meeting in '91: To what degree does the addition of progestin affect the possible risk of breast cancer induced by using estrogen alone? And does the addition of progestin blunt the protective effect of estrogen against heart disease and death in women?

"The data are not yet adequate to permit an answer (to these questions)' was the reply.... Notwithstanding, the FDA committee stated that this combination of hormones 'may be used indefinitely by a woman with a uterus....'

"Believe it or not, no study has been completed in North America on the possible carcinogenic consequences of the combined-hormone therapy routinely prescribed for women in menopause. 'Hormone replacement which includes systemic progestin...may be beneficial, but it is at least as likely to be harmful,' concludes a review of studies by T.M. Mack at the University of Southern California....' It's the largest uncontrolled clinical trial in the history of medicine,' charges public health expert Dr. Lewis Kuller.

"This was my introduction to the scandalous politics of menopause."

**The Change: Women, Aging and the Menopause**, by Germaine Greer, Knopf, 1992, \$24.

The publisher describes this as a book that will "challenge all our accepted notions about the physical and emotional effects of menopause and aging." Greer ranges over a 200 year period to



provide a cultural history of how menopause has been viewed and treated. Her chapter headings are true to her personal style, and include The Undescribed Experience, All Your Own Fault, Medical Ignorance, Misery, Grief, Sex and the Single Crone, The Aged Wife, The Hardy Perennials, The Old Witch, Serenity and Power. This is how her book ends:

"While the anophobes draw frightful caricatures of the untreated menopausal woman, and the hormone replacers rend their garments and bemoan the tragedy of the cessation of ovulation, women themselves remain silent. Let younger people anxiously inquire, let researchers tie themselves in knots with definitions that refuse to stick, the middle-aged woman is about her own business, which is none of theirs.

"Let the Masters in Menopause congregate in luxury hotels all over the world to deliver and to hearken to papers on the latest astonishing discoveries about the decline of grip strength in menopause or the number of stromal cells in the fifty-year-old ovary,

the woman herself is too busy to listen. She is climbing her own mountain, in search of her own horizon, after years of being absorbed in the struggles of others. The way is hard, and she stumbles many times, but for once no one is scrambling after her, begging her to turn back. The air grows thin, and she may often feel dizzy. Sometimes the weariness spreads from her aching bones to her heart and brain, but she knows that, when she has scrambled up this last sheer obstacle, she will see how to handle the rest of her long life. Some will climb swiftly, others will tack back and forth on the lower slopes, but few will give up.

"The truth is that fewer women come to grief at this obstacle than at any other in their tempestuous lives, though it is one of the stiffest challenges they ever face. Their behavior may baffle those who have unthinkingly exploited them all their lives before, but it is important not to explain, not to apologize. The climacteric marks the end of apologizing. The chrysalis of

conditioning has once for all to break and the female woman finally to emerge."

**Menopause, A Self-Care Manual**, Santa Fe Health Education Project, 1989, \$6.75 from the authors at Box 577, Santa Fe, NM 87504; Spanish version \$3.75.

This isn't a new book, but we add it now because it developed from menopause workshops. The emphasis is on "Taking Care of Ourselves" and "Natural Remedies—Self Help." They are conservative on HRT and remind readers that this treatment "must still be considered experimental, at best...Somebody makes a lot of money when women buy so-called antidotes to the normal aging process."

Of all these books, the first two are the most useful. I've given detailed information so that readers can ask at their libraries or bookstores for the Perry, Sheehy and Greer titles. The first and the last listed both need to be ordered directly from their publishers.



## Join DES Action!



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

- ☐ Benefactor: \$1000 and above    ☐ Supporter: \$100  
☐ Sustainer: \$500    ☐ Friend: \$75  
☐ Associate: \$200    ☐ Subscriber: \$50-\$25 (sliding scale)

☐ I am enclosing my annual payment of \$ \_\_\_\_\_.

☐ I would like to donate through the **Pledge Program** with ☐ quarterly or ☐ semi-annual payments totalling \$ \_\_\_\_\_.

☐ Check enclosed (please make payable to: **DES Action**).

I am a: ☐ DES Daughter ☐ DES Son ☐ DES Mother ☐ Other

name \_\_\_\_\_

address \_\_\_\_\_

city \_\_\_\_\_

state \_\_\_\_\_

zip \_\_\_\_\_

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*The Infertility Book*—A Comprehensive Medical and Emotional Guide, by Carla Harkness. Celestial Arts Press. \$14.95.

Carla Harkness has put together an easily understandable, up to the minute guide for people struggling with infertility. This book is one of the most comprehensive I have seen in my 13 years of working in the field. I especially like the charts in the book, which are used for comparison and clarification of tests, treatments, and adoption as an option.

*The Infertility Book*, in addition to having a full bibliography, list of resources, and glossary of

terms, is well organized and provides up to date information on: artificial insemination, hormonal problems and treatment, male infertility, endometriosis, adoption, surrogacy, the economics of infertility, immunological and unexplained infertility, medical facts and emotional aftermath of pregnancy loss, pregnancy after parenting, childfree living.

As a DES daughter who struggled with infertility many years ago, my greatest need was for validation of my emotions. It is here where *The Infertility Book* shines. Ms Harkness' book is laced with true-to-life vignettes. Indeed, I read much of these through a veil of tears. These are the stories and emotions readers might want to share with well meaning friends and relatives as

a way to help these people learn what helps and what doesn't in their efforts to be supportive.

Since adoption was the option chosen by my husband and myself, I want to share with you the following excerpt from the book:

"I don't think it is easy for a woman to accept the fact that a life may never grow within her. But it is harder to imagine never experiencing the joy and pleasure of raising a child. I will always wish that I had actually carried my son and given birth to him. I feel the loss of those nine months even while I cherish the blessing of having him as my son for the rest of my life. But I have come to realize that pregnancy lasts a very short time; raising a child lasts a lifetime."

—Andrea Goldstein.

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