A FOCUS ON DIETHYLSTILBESTROL

Spring 1995

#64

### **Notes from Nora**

## New Informational Booklets Available

s we go to press, the National Cancer Institute is printing eight new informational booklets about DES, to be distributed to consumers and health care providers nationwide.

These booklets are for you and for all DES-exposed people. They will be utilized as part of the National DES Education Program, a five-site program testing different methods for reaching the many people who do not currently know they were exposed to DES. Thus they are written as introductory materials, and include medically accepted information about the health effects of DES and medical recommendations for DES-exposed individuals.

DES Action Board members and staff have been active participants in the writing of all these materials.

What follows is a description of each booklet and ordering information.

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#### The Basic Booklet

Cover: Were you born between 1938 and 1971 or Pregnant Then? If so, you could be exposed to DES.

This booklet is the 'encyclopedia,' a brief review with information on DES exposure for DES mothers, daughters and sons. Also includes information on finding out about exposure and tracking down medical records. 44 pages.

#### **Introductory Booklet**

Cover: Were you born between 1939 and 1971 or Pregnant Then? If so, you could be exposed to DES

Shorter version of the Basic Booklet, with a brief overview of information for all DES-exposed. Recommended for people who are unsure of their exposure or wish to read a shorter booklet. 16 pages.

#### **DES Daughters Booklet**

Cover: DES Daughters: Women Born Between 1938 and 1971 Who Were Exposed to DES Before Birth

Complete overview of all health risks and recommendations for DES daughters. Recommended for women fairly sure of their exposure. 36 pages.

#### Women Who

Took DES and Breast Cancer Cover: Women who Took DES: A Guide for Women Who Took DES During Pregnancy From 1938 to 1971.

Short booklet discussing breast cancer risk and recommendations for women who took DES; also sections on talking with your DES-exposed children.

8 pages

## Talking about DES: A Guide for Families

Cover: Talking About DES: A Family Guide for DES-Exposed Mothers, Daughters, and Sons

A guide for DES mothers, daughters and sons about how to bring up and discuss the topic of DES exposure. A brief review of health effects for each group. 16 pages.

#### Clear Cell Cancer

Cover: Clear Cell Cancer: Resource Guide for DES-Exposed

continued on page 4

#### L D L U M C T I U

### **DES Action Affiliates**

Each group was created and nurtured by volunteers. Write them if you want information on their activities or can volunteer.

DES Action/USA National Offices 1615 Broadway, Suite 510 Oakland, CA 94612

L.I.J. Medical Center New Hyde Park, NY 11040

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Michigan P.O. Box 2692 Ann Arbor, MI 48106

2205 Rosewood SE Grand Rapids, MI 49506

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Minneapolis, MN 55403 Missouri 7647 Carswold Clayton, MO 63105

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Rumford, RI 02916 Texas 8230 Shadowwood Drive

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**DES Action/Ireland** 32 Upper Fitzwilliam St. Dublin 2

DES Action/Italia Centro Simonetta Tosi Casa Intern Donna Via della Lungara 19 00165 Roma

DES Action/Netherlands DES-Aktiegroep Wilhelminapark 25 3581 NE Utrecht ES (diethylstilbestrol) is a synthetic form of the female hormone estrogen. From 1938 to 1971, several million pregnant women in the U.S. were prescribed DES, especially if they had a history of previous miscarriage or slight bleeding or had diabetes. DES was given in pills, injections and suppositories and sold by over 200 drug companies under their own brand names.

DES exposure can lead to health problems:

DES mothers have a slightly increased risk for breast cancer

DES daughters have a 1 in 1,000 risk for a rare vaginal/cervical cancer, clear-cell adenocarcinoma. This is the reason all daughters need regular gyn exams. They also are at risk for reproductive difficulties: infertility, ectopic pregnancy, miscarriage and premature delivery, and should always receive high-risk pregnancy care.

DES sons have an increased risk for undescended testicles, cysts on the epididymus, and possibly for infertility

DES Action, the major consumer group working on this issue since 1974, has special publications, physician referral lists, attorney referral lists, this quarterly newsletter, and a hotline: 1-800-DES-9288.

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# book review

# The New Ourselves, Growing Older

A Book for Women over Forty, Women Aging with Knowledge and Power

Paula Doress-Worters and Diana Laskin Siegal, in cooperation with the Boston Women's Health Book Collective. 1994. Simon and Schuster. \$18.00. 531 pp.

This is a revised and up-dated version of the 1987 book, with new chapters on menopause, HIV/AIDS, breast cancer, cosmetic surgery. It's the size of a telephone book and covers just about every topic in major sections titled: Aging Well; Living with Ourselves and Others as We Age; Understanding, Preventing and Managing Medical Problems; Resources.

The chapter on menopause will be of particular interest to many DES daughters who are now in or approaching their forties. The authors cite a 1993 report by the National Women's Health Network on the risks and benefits of hormone use:

Many women have an intuitive understanding of a little-known statistic. The average women who dies of heart disease loses eight years of life. Women who die of breast cancer lose, on average, nineteen years. Many women are uncomfortable taking a chance of increasing their risk for a disease which is always devastating and if fatal, often kills at a relatively young age.

The authors go on to add their view:

Standards for using unproven treatments on healthy populations

"There is a crucial difference between aging and disease."

should be more stringent than those for treating persons who are ill and choose to risk something new as a possible cure. We question the ethics of attempting to flood a healthy population with an unneeded medication that may result in new risks. In any other situation we would call this an experiment.

Whether you take hormones or not, whether you take them for shortterm relief of discomforts, or longerterm prevention of disease, is your decision. You will want to consider your own history, values, health status, and preferences as well as your understanding of the research studies.

Consider your choices carefully, but remember that the choice of hormone therapy or not is only one aspect of your change of life. Menopause is a normal part of a women's life experience. We can learn from one another ways to manage the typical discomforts that occur. Our focus must be on our own growth and development as we contemplate the changes we want to make for ourselves during these and the following years. We must not be manipulated into regarding this important turning point in our lives as merely a choice point about medications.

Introducing the final major section on medical problems, the authors point out that

Women are treated with less

respect within the health-care system and receive poorer medical care than men. As we age we are in double jeopardy because the widespread bias and discrimination against older people that is so deeply ingrained in our culture exists even among the people and institutions we turn to for help and support.

Ageism manifests itself first and foremost in the attitude that aging is a disease. Gerontology, meaning the study of the aging process from maturity into old age, as well as the study of older people as a special population, is often confused with geriatrics, the medical treatment of old people. Because of male domination in medicine, researchers have emphasized general problems or male problems, without noticing that women experience aging and illness differently.

Aging is not a disease

There is a crucial difference between aging and disease. Both happen at all ages but health-care providers and researchers don't always distinguish between the signs of aging and symptoms of disease.

If we recognize that a particular problem is probably a symptom of disease rather than a normal part of aging, we will be more likely to seek solutions for it. Even if a cure for the disease is not available, specific interventions may help us live more comfortably.

The book then describes the present medical care system, the need for change, how to begin getting better medical care.

Ourselves Growing Older is an essential reference book for all of us.

# The "Safe" Prevention Option

By Linda Appel, National Women's Health Network News March/April 1995

espite all of the attention that the Tamoxifen Breast Cancer Prevention Trial has received, we at the National Women's Health Network want to make women aware that there is another, safer trial currently underway—the Women's Health Initiative, sponsored by the National Institutes of Health.

This prevention trial will examine what has been a controversial issue within the cancer research community: the relationship of a low fat, high fiber diet and exercise to cancer prevention. Instead of using a potentially harmful drug on healthy women to try to ward off cancer, this study will teach postmenopausal women how to live a healthy lifestyle by eating a low fat diet and exercising. No drugs.

"This study
will teach postmenopausal women
how to live a healthy
lifestyle by eating a low
fat diet and exercising.
No drugs. No risks."

No risks. No possibility of secondary cancers. If you are interested in participating in the Women's Health Initiative's Breast Cancer Prevention Trial, recruitment is currently taking place at sites throughout the United States. Contact the National Institutes of Health at 1-800-54-WOMEN for a list of sites and additional information.

BOOKLETS from page 1... Daughters and Their Families A comprehensive review for women diagnosed with clear cell cancer and their families. 42 pages.

#### **Facts About DES**

A two pages summary of the main health effects and what to do about them. Good for those first approaching the subject. 1 two-sided page.

# National DES Education Program: A Description

Two page summary of the National DES Education Program. Mainly for the press and those interested in learning more about the National DES Education Program.

1 two-sided page.

#### Still to Come

(estimated publication date: June/July):

#### **DES Sons Booklet**

A comprehensive review of the health effects and health care recommendations for men exposed to DES before birth.

At this writing, plans for distribution to the general public were still being arranged. We recommend that you contact the Cancer Information Service at 1-800-4CANCER (1-800-422-6237) to request any of these booklets. They are free of charge. If you have any problems obtaining the booklets from the Cancer Information Service, please call DES Action at 1-800-DES-9288 (1-800-337-9288).

#### Help Spread the Word

Hardly a day goes by without continued on page 8

# \* medical report

"Onset of menopause in women exposed to diethylstilbestrol in utero," Paige P. Hornsby, Ph.D., Allen J. Wilcox, M.D., Ph.D., and Arthur L. Herbst, M.D. American Journal of Obstetrics and Gynecology, January 1995.

This study uses the Dieckmann group—daughters born to mothers from the 1951/52 trial of DES at the University of Chicago—who at the time of the 1990 telephone interviews were 37 to 39 years old. There were 296 exposed women and 246 unexposed women, and the DES daughters reported a greater frequency of irregular cycles, lack of menstruation, or heavy or prolonged bleeding. However, the researchers found only one medically documented case of early menopause, which they describe as "within the range of what would be expected on the basis of data from a group of women followed up over time for assessment of age at natural menopause." Their conclusion was that "there appears to be no relationship between prenatal DES exposure and diagnosis or symptoms of early menopause."

They also reported that 10% of the DES-exposed women, compared with 4% of the unexposed, had ovarian cysts removed, and that "this possible effect of prenatal DES exposure deserves more thorough study."

### **DES Third Generation Network**

(Reprint of a speech by DES Third Generation Network Director Elizabeth Wandelmaier)

In October, 1994, DES Action members gathered for a national meeting in Norwood, Massachusetts. Elizabeth Wandelmaier, Director of the DES Third Generation Network, gave the following talk. We present it here so that you have an opportunity to learn more about the work of the Third Generation Network.

"I would like to introduce the DES Third Generation Network.

"We are DES daughters who have given birth to children with problems, ranging from minor to severe.

"Certainly not all DES daughters who have children, have children with problems. How many do? I don't know. Until we gather more information, we can't know. We need to hear from other DES daughters, or possibly sons, who have children with problems.

"Most of the DES daughters who have so far gotten in touch with me have had babies prematurely. Some of the expectant mothers were on anti-contraction drugs. Many of the expectant mothers were on strict bed rest, some with contraction monitors, and they still had the babies prematurely. Some of the premature babies did not survive. Some of the surviving babies have lasting disabilities. Some have cerebral palsy, which means they can't use their bodies for walking, or to control a pen for writing. Cerebral palsy results from brain damage.

"Several of the children have damage to their cognitive abilities, also from brain damage. "Certainly not all DES daughters who have children, have children with problems.

How many do?
I don't know."

Some have learning disabilities, attention deficit disorders, or developmental delays.

"Most of the third generation children are not yet in adolescence. But some of those who have reached adolescence are having gynecological abnormalities including menstrual problems. One seven year old girl is beginning to go through puberty.

"I have two daughters. My first daughter, eight and a half years old, seems healthy, but she is not yet in adolescence. I'm afraid she may develop my many gynecological problems, or new ones. My second daughter, four years old, has severe cerebral palsy and other problems because of brain damage.

"The DES Third Generation Network was formed to give DES daughters and sons with children a way of contacting each other for support and to share information. I started this because I want answers. How common are these problems? How severe are the disabilities? I want to get information available for others to make an informed decision about whether to pursue pregnancy, and how to contact those of us in the same boat.

"We have started a List. The List has, for each DES daughter, a short description of her child's problems. The description for my younger daughter reads: 'Rose was born eight weeks premature and has severe brain damage. She has severe cerebral palsy, minimal eyesight, a seizure disorder, and developmental delays.' Her maternal grandmother took DES in 1954.

"If you know of a grandchild of a woman who took DES, and that grandchild has disabilities, please have the family get in touch with the DES Third Generation Network. We are listed on page two of each issue of this newsletter.

"We have unanswered questions. Do you know DES daughters with handicapped children? Do you know DES sons with handicapped children? We need to hear from them, and we need answers.

"The medical establishment, in my experience and the experience of other DES daughters I have spoken with, does not support the connection between DES and a grandchild with disabilities. If enough of us get together, we may be able to prove otherwise.

"The DES Third Generation Network List is the place to start. We can document the continuing tragedy that has so far been denied by the medical community.

"And we can help DES daughters and possibly sons learn to deal with not only the disabilities of their child, but the emotional pain it causes to know that one's own body, because of DES, has caused damage to one's own child."

### letters to the editor

I am very interested in hearing from any DES daughters who have not experienced good ovarian stimulation while taking Metrodin/Pergonal.

I have completed two IVF cycles and in both cases (each with a different Metrodin/ Pergonal protocol) I have not had good ovarian stimulation certainly lower than my physician anticipated. I am 36 years old and my hormone levels are within the normal range. I am curious if this poor stimulation may be attributable to my DES exposure. I will be undergoing a third (and final) IVF cycle in early June. I would very much like to hear from anyone who has had a similar experience.

Susie 221 Main St., # 600 San Francisco CA 94105 (415) 243-3740

Thank you! For the GREAT GREAT article on a childfree life. I cannot begin to tell you how much I appreciated hearing these words and how much I needed to hear them. More! You spoke DIRECTLY to me and I really appreciated your not glorifying or demonizing anyone's choices. This was one of the best examples of support for this lifestyle I've ever seen. An articulate mature piece of communication—thank you many many times from the bottom of this DES child??? daughter's heart.

Member for many years

I was extremely pleased to FINALLY read an article about couples who do not choose the emotional roller coaster ride of

infertility treatments. My husband and I made a rational decision after we had consulted with an infertility specialist. We then chose to be childfree.

The one point that you did not mention in your article was the pressure one feels from other infertile couples to seek infertility treatments. Ironically, this has been my experience. One of these couples had twins and the other adopted. I am sure that they are as happy with their decisions as my husband and I are with ours.

Reader, Florida

First of all I would like to thank you for the great information located in the DES Action **Voice**. It's very informative, as well as interesting and helpful.

I would like to respond to the Ouestion and Answer section (Voice 63, p. 5), the question being, "Is it safe to be on the pill?" The response was that in your study, you could see no problems. I am a DES daughter and would like to share my experience with you regarding

this issue.

I went on the pill in the early 80's. About six months later I developed pre-cancer cells located on my cervix. They ranged from moderate to severe. I had cryosurgery to remove the cells.

I had no regrowth of these cells until the early 90's. Again, I started the pill and about six months later I developed mild dysplasia.

I am curious if any other DES daughters have experienced precancer cell growth within months of taking the pill.

On another subject, I recently found out that I have a condition called "luteal phasedefect" which means the amount of progesterone does not adequately prepare the uterine lining for pregnancy. I am wondering if this low progesterone level has anything to do with DES? Have you encountered this question from any other daughters?

LOVCATS@AOL.COM

### Confidentiality Assured

As a courtesy to our members, it is our policy that we never sell or rent your names and addresses to any other organization.

Next time you decide to honor someone with a gift or memorial tribute, think of DES Action. Our

Tribute Gift

program allows you to donate in someone's honor or memory.

# Some Tips on Library Research

By Martha A. Russell

search the medical literature as a hobby and these are some of my favorite spots. There are some new sources which make researching DES and other health related issues much easier. Most major American newspapers are available on CD-ROM and also on some online services. Newspapers such as *The* Boston Globe, The Miami Herald, and The Los Angeles Times cover health related issues, review major medical studies for lay people and present human interest stories. Many public and college libraries have a regional newspaper on CD-ROM. These databases give you full-text articles but do not include pictures or charts. The search strategies and the indexing sometimes present a problem for beginners but with practice most people become comfortable looking for information with these tools. It is mind boggling the amount of information on health related issues that is contained in ten years of The Boston Globe on one

"There are some new sources which make researching DES and other health related issues much easier."

CD-ROM. If you use a CD-ROM in a library, watch the dates it covers and ask for the most recent one. Sometimes there is a gap of six months in coverage.

If you go online you do not need to worry about the coverage gap but you must be aware of the costs to access newspaper databases. During normal business hours some companies such as Dialog charge \$95 an hour to access these databases. If you wait for evenings or weekends you can access the same databases for \$25 an hour on Compuserve, or less on America Online. Beginners should first plan their search strategy and use menu-driven searches. If you need the information fast and

know what you are looking for, online searching is effective.

Several magazine indexes are available on CD-ROMs and on online services. Some provide abstracts of the articles and a few of the CD-ROMs provide fulltext articles. Many public and college libraries have such indexes on CD-ROMs. Again, the indexing and search strategies may vary but, with practice most people prefer searching with these tools than with traditional print versions. These indexes cover the popular press such as Time and Newsweek and often a few medical journals such as The New England Journal of Medicine. Different indexes cover different magazines so always check which ones are indexed. Also, some health newsletters may not be covered. Often libraries can get you books and articles on "inter-library loan" for free or for a modest fee.

If you have a home computer, a modem, and a telecommunicacontinued on page 8



city



## Join DES Action!



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

☐ Benefactor: \$1000 and above ☐ Sustainer: \$500 ☐ Associate: \$200	☐ Friend:	\$75 per: \$60-\$30 (sliding scale)	quarterly.' receive add	Those at the	he DES Action Voice \$100 level and above all reports on DES
☐ I am enclosing my annual pa ☐ I would like to donate throu	yment of \$ _				
☐ Check enclosed (please make	e payable to:	DES Action).		( <del>7</del> )	
I am a: DES Daughter 🗅	DES Son	☐ DES Mother of a ☐ Daugh	nter 🗆 Son	☐ Other	
name					<ul> <li>DES Action USA</li> </ul>

phone (

name address

state

1615 Broadway, Suite 510 Oakland, CA 94612 (510) 465-4011 #64

RESEARCH con't from pg 7... tions program, you can reach other information from your home. If you do not have a computer perhaps you have a friend who will give you a lesson. Many public and college libraries allow patrons to access their catalogs from home. If you have Internet access you can reach the Library of Congress and the National Library of Medicine. You cannot get full-text articles but you can get citations for books.

Some government agencies run BBSs (Bulletin Board Services) on health related issues. A BBS is a computer system that serves as an information and message-passing system. Using a computer, modem and a telecommunications program, you can reach the NIH (National Institute

of Health) BBS at 1-800-644-2271 and the FDA (Food and Drug Administration) BBS at 1-800-222-0185. Both have information which can be used by the average citizen. The FDA board includes an electronic version of the magazine FDA Consumer which discusses drugs and health topics.

Grateful Med (Summer 1993 DES Action Voice), an interface to the National Library of Medicine's computer, has competition from PaperChase. Grateful Med is run by the federal government while PaperChase, which was developed at Beth Israel Hospital in Boston, is run by a private company. Some people feel it is superior in giving novices access to the data in the NLM's computers. It is available in some college libraries and on Compuserve.

BOOKLETS from page 4...
a phone call or letter to us at the national office from someone who just learned that she or he is DES-exposed. We know there are many thousands of people who still don't know that their mothers took DES. We want your help in making DES information more widely available.

Now that these booklets are available, free, we want to make sure that public libraries have them in their health reference materials. You can put them there by getting a set from the Cancer Information Service and taking it to your library reference section. For those of you in cities with more than one branch, you can take the set to the main library and ask them to request copies for each branch.

# DES Action USA

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