A FOCUS ON DIETHYLSTILBESTROL

Winter 1990

#43

We Must Have Research

by Kari Christianson, Past President, DES Action

he "DES Research Symposium: Looking Back,
Looking Ahead" provided
a day-long forum in Minneapolis
in October. We had a chance to
review the known effects of DES
exposure and what research has
learned to date, to understand
where further research is needed,
and to formulate strategies for
stimulating funding for research.

Candice Tedeschi, an RNC and Coordinator of the DES Screening Clinic at L.I.J. Medical Center, opened the symposium with a history of diethylstilbestrol and its known effects.

Kenneth L. Noller, M.D., Director of the DESAD Project; Professor and Chair, Department of Ob/Gyn at the University of Massachusetts Medical School, provided an update on the DESAD Project and the need for continuing research. The DESAD Project has involved 25 physicians, 50 support staff, and 5,000 DES exposed and non-exposed

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There's no way that you can go back and reverse that programming because it happened at the early susceptible interval when all the DNA was getting organized for its secretory capability for the rest of the lifespan.

participants. The project was continuously funded from April 1, 1974, to July 31, 1989. At this time, all funding has ceased for the DESAD Project.

Dr. Noller reviewed the specific aims of the project and what has been learned from it. He is firm in the opinion that there are many additional questions about the effects of DES exposure which require more research. One such question concerns the incidence of clearcell adenocarcinoma. Dr. Noller stated: "One other fact that I think is very important: clear-cell cancer in a non-DES-exposed woman is a disease of the 50s and 60s age group....We don't know what's going to happen to DES women when they reach those ages. Are there going to be more cases? Is there a bimodal distribution with cases in the teens and 20s and more in the

50s and 60s? Or was this blip in the teens and 20s the only one we will see? We just don't know. This is one of the reasons we feel very strongly that these women are at high risk for life, that they need to be followed closely."

In addition to the need for continued exams and education for DES daughters, Dr. Noller would like research to follow several areas of concern that have been suggested by the DESAD Project to date. These include the incidence of neoplasia, the immune status, the occurrence of certain medical diseases and disorders, and the development of educational materials for primary caregivers. Another area of personal interest for Dr. Noller is the next generation, the "daughters of daughters." The significance of the DESAD Project research could continue to be far-reaching. Dr. Noller states, "This cohort, I think, is important for the human race.... I feel strongly that it is a real mistake to let the cohort disappear."

Arthur F. Haney, M.D., Director, Reproductive Endocrinology and Infertility at Duke University Medical Center, presented the fertility issues associated with DES. Of particular interest was Dr. Haney's discussion of the cells of the endometrium (lining of the uterus). He said, "If

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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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Insurance for Infertility Costs

California must now, under a new law AB900, offer coverage for the treatment of infertility (except IVF). DES Action was one of many organizations supporting this law, introduced by Assemblywoman Maxine Waters. While the law does not include individual health insurance policies, Ms Waters believes it may lead insurors to re-evaluate their practices and offer this coverage as an option.

The refusal of many health plans, such as health maintenance organizations, to offer this coverage is a serious concern for many DES daughters. If you live in a state that does not have this kind of law, you may want to ask your local representative to introduce a bill like AB 900. Our San Francisco office can send you a copy as a guide to legislators elsewhere.



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Our Wider World

Award for DES Action/The Netherlands

ne founders of our sister group in the Netherlands (DES Aktiegroep), Anita Direcks and Ellen 't Hoen, have been awarded the Harriet Freezer Ring. This prize, established in 1977, is presented annually by the Dutch feminist magazine Obzij to a woman or a grass roots organization that has an "awareness-raising and emancipating influence." Candidates for this prize are nominated by the readers of the magazine. The publicity involved means new opportunities to send out the message, "Were you born between 1947 and 1975? Maybe your mother took DES."

Our Latest Affiliate: Great Britain

Michelle Cowen, a 38 year old DES daughter, sparked the interest of a television documentary producer into doing a story on DES. It was shown on Thames Television on November 7th and followed with a chance for viewers to call in for more information. Michelle will never again have the feeling that she is the only DES daughter in the U.K.! She estimates that between 1,000 and 1,500 people tried to call, more than 500 people got through to the special group of 14 people staffing the phones, and another 150 left messages on the answering machine. Fourteen women reported that they had been suffering from cancer. One mother said that she was prescribed DES in 1956 in India

This prize is presented annually by Dutch feminists to a woman or a grass roots organization that has an "awareness-raising and emancipating influence."

from a German doctor. Her daughter died at age 17 from "cervical cancer." Because of this TV programme she made the link of her daughters death with DES, 16 years later.

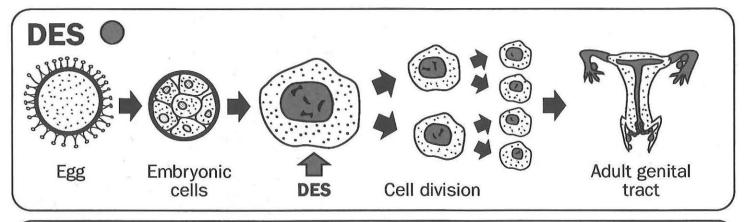
Many women knew they were DES exposed, but "it's a U.S. problem," doctors told them, and women did not know that they were not unique in being exposed. Doctors in the U.K. are not well informed about DES. Many physicians will perform incorrect exams and treatments. Women told stories about adenosis that is treated with laser or progesterone and about having had only a cervical Pap test. Some women said they had had an ectopic pregnancy or a miscarriage but their doctors denied any link to DES.

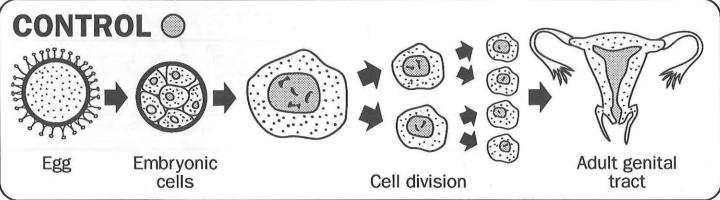
With the help of the Women's Health and Reproductive Rights Information Centre in London, a DES Action/Britain chapter has been set up at the Centre's offices: 52-54 Featherstone St., London EC1 Y 8RT.

Reaching the Third World

At the 21st International Congress of the Medical Women's International Association in Seoul, Korea, in August, the main theme was the worldwide incidence of cancer in women. The Dutch government supported the action of the Dutch delegates in submitting a resolution on DES, prepared with the help of DES Aktiegroep. The resolution, passed unanimously, called on the board of the MWIA to support initiatives for identifying, informing and supporting DES exposed mothers, daughters and sons; for information campaigns on DES for the medical profession, and for a complete ban on DES including measures to prevent the production and export of DES to the third world. In many third world countries, drugs like DES are sold over-thecounter without needing a prescription.

After a lecture on DES was given, the Dutch delegate reported that their colleagues in Africa, India and Latin America were mostly ignorant about the effects of DES on DES offspring. The doctors at the conference who came from developing countries emphasized the importance of spreading this information. Leaflets from DES Action were very useful, especially those in Spanish and Swahili (prepared initially for the International Decade of Women conference in Kenya in 1985).





Changed forever!

ting organized for its secretory capability for the rest of the life-span. Now, that's all sort of doom-saying about what the endometrium is going to do or what the cavity is going to be like."

Dr. Haney went on to say that the effect of this DES exposure is not an absolute one in every woman. The clinical implications of that observed change are not predictable for an individual patient. Future study of such changes is needed. Dr. Haney stated that the DES population should be followed very carefully and that the DES story is not over yet.

Sidney Wolfe, M.D., Director, Public Citizen Health Research Group, offered his expertise on what we as consumers can do about the cut-off of research funding. He stated, "I find the statement that....'the reason

Credit: Arthur F. Haney, M.D.

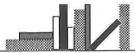
we're (NCI) not funding DES research is that it's all over and done with' is really unconscionable. The fact that no further cases are going to be caused is hardly a reason a) not to study, or b) not to notify people about it."

Dr. Wolfe offered encouragement for the rights of citizens and consumers in the legislative process. Political pressure and accountability can be exerted on our elected officials and NCI. Dr. Wolfe called consumer groups like DES Action "rays of hope" for causing change in our country.

Now, as never before, we the exposed population must be unrelenting in our efforts to work for funding of DES research.

Our symposium was made possible through a grant from the Sumner T. McKnight foundation.

SYMPOSIUM from page 1... you have DES exposure of an embryo, it forever programs that cell to act differently for the rest of its lifespan. And that's a principle that epidemiologists don't know, and developmental biologists do know, and that is, that the cells of the infant are very different than the cells of the adult. And they will stay different if you catch them with some agent like this in their very early vulnerable time. They will never respond the same. So what you have then in the DES exposed genital tract of the adult is a cell population within the endometrium that will spend a lot of its time acting in a different fashion than the endometrium of a normal woman. There's no way that you can go back and reverse that programming because it happened at the early susceptible interval when all the DNA was get-



book reviews

National Women's Health Network

Taking Hormones and Women's Health: Choices, Risks, Benefits 1989, 24 pages, \$5 from NWHN 1325 G St. N.W Washington, D.C. 20005.

This well-written booklet offers a careful look at estrogen replacement treatment (ERT): what is claimed, what research shows, and when ERT is appropriate. There is a thorough discussion of osteoporosis and ERT and of the risks and controversies in using ERT. The Network does not try to tell women what to do. It provides the information that readers need to make their own informed decisions.



Santa Fe Health Education Project

Menopause, A Self-Care Manual 1989, 71 pages, \$6.50 from the authors at Box 577 Santa Fe, NM 87504

The Project has been giving menopause workshops for over ten years, and draws on this experience. Chapters cover the physiology and signs of menopause, "cautions and considerations," and "taking care of ourselves." Some of the cautions are on ERT, hysterectomy, osteoporosis and breast cancer. "Taking care" includes natural remedies and self-help.



Kathryn S. Ratcliff, Editor Healing Technology: Feminist Perspectives 1989, 419 pages, \$14.95 University of Michigan Press, Box 1104 Ann Arbor, MI 48106

This book, with its focus on ways in which changing technologies affect women's health, has three major sections. "Reproductive Technologies: Economic and Social Implications" goes into what the new technologies mean, what the pressures are, and who makes the choices. "Health Care Technologies: Political and Ethical Considerations" refers to the male control of the production and distribution of technologies, and the sales of services to women. One of the chapters is on "The Meaning of Risk, Choice and Responsibility for a DES Daughter" by sociologist Susan Bell. The final section, "Occupational and **Environmental Technologies:** Research and Resources for Change" ends with chapters on women as activists, in their roles as workers, patients and citizens, to re-shape the development and use of technology.



Christine Overall, Editor
The Future of Human Reproduction
1989, 279 pages, \$17.95
from Women's Press
229 College St. #204
Toronto, Ontario. M5T 1R4,
Canada

This critical study on new reproductive technologies is centered on demonstrating that the implications of that technology are much more complex and far-reaching than we realize.

Although written for a Candian audience, this book serves a broader public since the concerns are not limited to one country. Harriet Simand of DES Action/ Canada has a chapter on "Fifty Years of DES—Fifty Years Too Many." She uses DES as an example of "many troubling issues that are still applicable concerning the testing of drugs, the long-term health implications of prescribing drugs to healthy women, the medical profession's capability and willingness to deal with iatrogenic problems, and the legal implications of reproductive technology."



Berger, Goldstein, Fuerst The Couple's Guide to Fertility 1989, 442 pages, \$12.95 Doubleday 666 Fifth Avenue New York, N.Y. 10103

The subtitle of "How New Medical Advances Can Help You Have a Baby" covers in detail medical and social facts in the beginning section on "What's Going On." This includes a special report on "The Damage Done by DES." Part two on "What You Can Do" covers fertility evaluation, hormone treatments, medicine and surgery, IVF and its cousins. In the final section on "Alternatives" the authors write about donations of eggs, sperm or embryos, and about coping with infertility-"When To Stop Treatment." United States and Canadian fertility specialists are listed in a 62-page appendix.

(2) letters to the editor

Dear Editor:

I would like to share with your readers a story with a happy ending.

Some years ago my daughter, now 35, had been asked by a gynecologist whether her mother had ever taken DES. I did recall that early in my pregnancy with her I had a slight episode of bleeding, and that at the behest of my doctor stayed in bed a day or two, and that was that. I had no memory of being prescribed anything, but felt that I should look into it. Fortunately, our clinic had old records on film and found mine. Indeed I had been prescribed DES! What an unhappy discovery; and how could I have not remembered! No doubt I thought it some magic combination of vitamins or the like. (Today's woman informs herself, happily). How long I took it or how faithfully I cannot say, but the dosage was sufficient to cause many problems for my daughter, conditions contributing to the inability to become pregnant being among the most distressing.

In time she decided to seek treatment with a fertility specialist in Little Rock, Arkansas. He prescribed Clomid and treated her for a hormonal imbalance traced to a thyroid condition, perhaps brought on by stress. This did achieve a better balance, but still no success in becoming pregnant. Further examination revealed a T-shaped uterus, a condition that poses the possibility in pregnancy of premature labor. This and a slightly deformed Fallopian tube found and corrected during a laparoscopy

procedure were certainly manifestations of DES. It was found that she had not been ovulating. Opening the Fallopian tube, plus a few other corrections performed during the procedure, as well as her continued use of Clomid, induced ovulation. One month later she became pregnant! What joy. Still, there was to be faced the possibility of premature labor.

She was very fortunate to have recommended to her an obstetrician who had successfully delivered many babies of DES daughters. His "up" attitude and proposed program of close monitoring of the pregnancy inspired in the prospective parents a feeling of confidence and trust.

The pregnancy went well, past the seventh month, then at the end of the eighth month her labor began. It was not unduly long, but because the baby had not gone to full term and was not in a correct position, he was helped out with forceps. Neither mother nor baby were the worse for it. He weighed just under 6 lbs. and required no special care. The mama recovered quickly and is now nursing a darling baby boy. The parents are not ruling out production of another someday.

May this account bring hope to young women who are now feeling as discouraged as my daughter had been; and to mothers who feel as distressed and helpless as I had felt.

My daughter invites inquiries from anyone who wishes to write to her: Betsy Taylor, Rt. 1, Box 112 A2, Redfield, AR 72132.

Helen Noble

Dear Editor:

When my father died last January, my family decided to ask our friends to contribute to a memorial fund at DES Action. The Jack Dandridge Memorial Fund has been designated by our family to be used for DES Action's work in educating nurses and doctors about DES.

This kind of "tribute" donation can be used to honor many special occasions, not only the sad ones. Birthdays, weddings, graduations: gifts to DES Action are an investment in our future knowledge and health. The national office in San Francisco thanks each donor and informs the person honored that a gift has been made in their name. My father believed in DES Action and would be proud of this memorial in his name.

Vickie Dandridge

Support Groups

rom time to time people call us to find out if there is a DES support group in their area. We often have to tell them that there is not. If you'd like to get together with other DES-exposed people to discuss common concerns, we can put your request, together with your name, phone, and city, in the VOICE. The rest is up to you.







Our Days in Court

Supreme Court Upholds New York Law

he U.S. Supreme Court announced on October 30 that it would not hear appeals by the drug companies against the New York State court decision upholding market share liability. The Supreme Court in 1980 upheld a similar California decision, and as DES plaintiff attorney Paul Rheingold told the Wall St. Journal, "When New York and California go one way it has a tremendous influence on other states, especially small ones."

What this means for DES daughters in these states is that specific product identification, once required in a product liability suit, is no longer necessary. The *New York Times* of October 30 described this victory in these words "The Supreme Court today let stand one of the most far-reaching rulings ever issued by an American court." It went on to quote the written opinion by Chief Judge Sol

"The
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American
court."

Wachtler of the New York Court of Appeals that the basis of liability was not the sale of a particular pill to a particular person, but "marketing the product. It is merely a windfall for a producer to escape liability solely because it manufactured a more identifiable pill, or sold only to certain drugstores."

Hundreds of suits that were held up until this issue was settled will now go forward in New York courts.

Success in California

In California, a victory on the statute question in the suit of LuEllen Shewmaker. According to a decision by the California Supreme Court in April 1988, plaintiffs must file suit within a year of their injury. Ms Shewmaker's attorney, Roman Silberfeld, argued before a Los Angeles jury that she filed her lawsuit 17 months after cancer surgery because she did not know within the statute year that she was exposed to DES, that DES had caused her cancer, and that there was wrongdoing on the part of the drug companies.

The television message that DES Action prepared, starring Linda Kelsey, was the way the Shewmakers learned about DES and its effects, and this TV spot was shown to the jury. After one and a half days of deliberation, the jury returned a verdict for Ms Shewmaker on the first ballot, so now her suit can go forward.





Join DES Action!

 ${f Yes}$ - I want to get the answers about DES. Enclosed is my membership.



☐ Benefactor: \$1000 and above	☐ Supporter: \$150	All members receive The DES Action Voice
☐ Sustainer: \$500	☐ Friend: \$75	quarterly. Those at the \$75 level and above
☐ Associate: \$250	☐ Subscriber: \$50-\$25 (sliding scale)	receive additional annual reports on DES
		Action's work and progress.

☐ I would like to start my membership of \$	_ through the Pledge Program (\$75	/year or more).
Enclosed is my first u quarterly or semi-annual	al payment (choose one) of \$	

I am a: DES Daughter	☐ DES Son	☐ DES Mother	□ other
Please make checks paya	ble to the D	ES Action Voice	

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* * dear doctor

Is pain with intercourse associated with DES exposure? Do common DES changes such as adenosis or cervical abnormalities; or less common changes such as vaginal bands or septae, interfere with sexual sensations or with intercourse?

Pain with sexual intercourse (dyspareunia) is a common problem and arises from a large number of causes. Commonly occurring secondary to psychological factors, it is always essential to evaluate and rule out physical causes first. It is possible to separate the causes of painful or difficult intercourse into those

arising at the vaginal opening (usually related to infection, local lacerations or ulceration, etc.); those arising deep in the vagina which will be noted with deep penile penetration (often related to inflamed tubes and/or ovaries, cysts or endometriosis) and those which arise from the midvagina or "vaginal barrel" (vaginal constrictions, "bands" or septae or vaginal narrowing).

It is the latter group of conditions that may occur in a DES-exposed woman who has any of these findings.

Generally, the vaginal canal has sufficient elasticity that even in the presence of these findings women have little discomfort during sexual activity.

Clearly, the presence of pain during intercourse can be a significant factor in interfering with sexual function and orgasm. It is very important for the gynecologist to avoid attributing dyspareunia and lack of orgasm to these changes unless a relatively certain association can be shown.

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