

Medical Reports

Reviewed by Pat Cody

"Infertility among women exposed prenatally to diethylstilbestrol,"

J.R. Palmer et al, American Journal of Epidemiology, Vol. 154, No. 4, 2001.

IN our Fall 2000 issue of the VOICE we reported on the abstract, or summary version, of this study. The abstract lacked the detailed information we now have from the publication of the entire report earlier this year.

This study collected data in 1994 on the fertility status of 1,753 DES daughters and 1,050 unexposed women. The median age of the women was 42 at that time. 24% of the exposed and 18% of the unexposed had never become pregnant. The researchers found that infertility in DES daughters was most often linked to uterine or tubal factors.

An interesting finding was that for the DES group, those exposed before 9 weeks of pregnancy had a never-pregnant rate of 30.2% and those first exposed

Reason for infertility among DES daughters

	DES exposed	Non-exposed
Tried to become pregnant for at least 12 months without success	1,260	884
Had difficulty conceiving because of:		
Uterine problem	24	2
Tubal problem	33	9
Hormonal/ovulatory problem	57	28
Endometriosis	17	9
"Other" problem	13	3
More than one type of problem	64	14
Unknown type	174	64

later than 13 weeks of pregnancy the lowest rate among this group, 20.5%. This fits with what we have learned from embryology, that the reproductive tract develops in the early weeks of fetal life, so that an interference from DES could affect that development.

...

Editor's note: The study could help DES daughters seeking legal compensation for infertility resulting from their DES exposure. Contact us for referral to an attorney who handles DES cases.

"Prenatal DES exposure: the continuing effects" by Arthur F. Haney M.D., Director, Reproductive Endocrinology and Infertility, Dept. of Ob/Gyn, Duke University Medical Center, in OBG Management October 2001.

WITH his many years of experience with DES daughters, Dr. Haney reminds other physicians that "exposure to DES in utero may cause higher rates of spontaneous abortion, premature labor, and ectopic pregnancy. And since many exposed women are still of reproductive age, continued vigilance of these women is essential."

He points out that the uterine lining of a T uterus appears

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Update on DES Internet Listservs

by Sally Keely (aka "DESxposd")

THERE are now several DES e-mail lists.

DES Action members with e-mail access are invited to join the DES Action Listserv, DAL. The purpose of this listserv is to allow a direct e-mail link between DES Action and our members. This forum is primarily for information sharing, for instance: Legislative alerts, Press releases and news updates, Event announcements, e.g. DES Symposiums, Information from upcoming DES Action Voice newsletters.

This low volume list is a benefit of membership. Only current DES Action members may participate. To subscribe, send e-mail to Sally Keely, the list owner, at DAL-OWNER@perilpoint.com. Please include a statement that

you wish to join DAL and the full name under which your current DES Action membership is listed. Note: this list has recently moved to a new server, so these are new subscribe directions. All 95 previous list members have already been transferred over to the new site. If you have any questions about the list, please contact Sally.

DES daughters should check out DES-L, the DES daughters listsev and online support forum at http://www.surrogacy.com/online_support/des/. To join the listserv, complete the online application and get ready to share support and information with 1000 other DES daughters!

DES sons will want to join the DES-Sons list for confidential

discussions of issues related to DES exposure in males. This list was developed in conjunction with DES Action. To subscribe send blank e-mail to des-sons-request@egroups.com. Direct questions to des-sons-owner@egroups.com.

The DES-Family list welcomes all DES-exposed, their family, and friends. To join, e-mail listserv@sact.com with only the command "subscribe des-family" (without the quotes) in the body of the message.

Charli@egroups.com can help if you have questions.

Lastly, announcing the newest DES related listserv, DES-Pregnancies. DES daughters who are pregnant, trying to conceive, or contemplating pregnancy are invited to join via the list website <http://www.onelist.com/subscribe/despregnancies>. You will need to register with onelist, if you aren't already. Contact ladonnakat@aol.com if you have trouble subscribing.

DES Action Affiliates and State Contacts

DES Action Affiliates

Each affiliate was created and nurtured by volunteers. Write to them if you want information or would like to volunteer.

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State Contacts

State contacts participate in national projects organized by DES Action. Contact the national office if you would like to find out about our national projects.

Arizona
Los Angeles, CA
San Diego, CA
Grand Rapids, MI
New Jersey
New Mexico
Ohio
Oregon
Texas

DES Action International

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Canada
England
France
Ireland
The Netherlands
New Zealand

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National Recognition for DES Concerns

DES Action has been invited to become working members of three important national committees:

THE NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES (NIEHS), one of the 18 Institutes of the National Institutes of Health (NIH), is well known to us for its work on the mouse model and DES effects. Now the NIEHS is setting up a Lay Advisory Committee of people from public interest organizations across the nation, and our Board President Molly Spira will represent DES Action with this group.

Plans are for the committee to meet twice a year to learn about various areas of NIEHS work, give advice, and provide input for new areas of research. Our letter of invitation from Kenneth Olden, Director of the NIEHS, began with, "I am writing to ask for your help in shaping the future investments of the NIEHS." Molly will be one of 25 representatives from a variety of consumer health agencies.

Kari Christianson, past-President and current Board member, and Executive Director Nora Cody continue to represent DES Action in a coalition of independent health organizations working to educate people about real prevention and public health. The coalition formed in response to the aggressive advertising promoting the powerful breast cancer drug tamoxifen for healthy women, and has gone on to work for a stronger ethical standard in direct-to-consumer drug advertising. We also work to educate people that prevention does not necessarily come in a pill, but from reducing or eliminating hazardous substances in our environment that cause cancer and other diseases.

THE NATIONAL CANCER INSTITUTE (NCI), the largest of the NIH Institutes, invited our Program Director Pat Cody to join a Consumer Advocates in Research and Related Activities (CARRA) program. A total of 150 members who are cancer patient advocates will work with the NCI staff, scientists and clinicians to improve and enhance NCI research. CARRA director Yvonne Andejski wrote that "Today we are at a starting point. Your task as a founding CARRA member is to set an unprecedented standard for effectively representing your constituency—the consumer advocate community—and become an increasingly valuable resource in the work of NCI, and your constituency's perspectives will most certainly contribute to the success of this new initiative."

CARRA's ambitious program includes setting research priorities, evaluating clinical trials, identifying gaps in current cancer research, developing and reviewing information for the public, and participating in activities to address national issues, such as differences in health care delivery in the U.S., and serving on the Advisory Council of the National Center for Complementary and Alternative Medicine.

Informing Pennsylvania

THANKS to the hard-fought efforts of Board member Jean Golomb and other volunteers in Pennsylvania, the PA Dept. of Health began a state-wide campaign in April. Board member Jean Golomb is shown here presenting Senator Arlen Specter with an award for his support for our national funding. Jean organized and chaired a DES Education and Awareness Conference on April 21 with speakers that included Marsha L. Vanderford, Ph.D., from the national education campaign at the Centers for Disease Control; DES Specialist Candy Tedeschi, Nurse Practitioner; Victor Greco M.D., past President of the Pennsylvania Medical society on "DES and the Medical Professional"; lawyer Brandon Levine on "DES—Current Legal Issues"; and "DES Awareness in Pennsylvania" by State Senator and DES daughter Lisa Boscola, who sponsored, at Jean's urging, the appropriation for the state campaign.

This extensive campaign included a letter and materials sent to over 10,000 Pennsylvania doctors as well as to health newsletters and hospitals. Advertisements were broadcast continuously over 41 major radio stations. Here is what they said:



Board member Jean Golomb and Senator Arlen Specter

"Did you ever think you'd need to turn the tables and ask your mom about drugs? Well, there's one drug you should definitely talk to your mother about: diethylstilbestrol, or DES. From 1938 to 1971, DES

"Talk to your mom today and find out if you might have been exposed to DES; it could change your life."

was prescribed under many different brand names to women who had complications

with pregnancy, especially miscarriages. However, it was later discovered that DES can cause health problems in the women who took the drug, as well as their children. So, if you took DES, or if you think your mother may have taken DES while pregnant, talk to your doctor and call 1-800-DES-9288 for more information. Talk to your mom today and find out if you might have been exposed to DES; it could change your life. Call 1-800-DES-9288. This message brought to you by the Pennsylvania Department of Health.

Tom Ridge, Governor. We're there. For your health. For your community."

You'll note that is our 800 number they give. We knew when the campaign began on August 3. When we got to work the calls had begun and the phone was ringing constantly all month long. We had over 2,500 calls that month, including some from states next to Pennsylvania, who heard the radio message. We worked overtime and mailed close to 2,000 free information packets to residents of Pennsylvania, New Jersey, Delaware and Ohio. ■

E

strogens in plants

"Endocrine disrupters and flavonoid signalling" by Jennifer Fox et al, *Nature*, 13 Sept. 2001.

WE know that some chemicals like DDT and bisphenol A (a byproduct of plastic manufacture) can have a disrupting effect on the endocrine systems of animals, especially on their reproductive systems. Now the Environmental Endocrinology Laboratory of the Center for Bioenvironmental Research at Tulane University has widened this concern.

They have done a study on how such chemicals can disrupt

plant life as well, including important food crops. Some plants communicate with soil bacteria by producing plant estrogens that attract bacteria to live in their roots. Bacteria in the roots of these plants convert nitrogen from the air into a form that is used as "natural fertilizer" by the plant. This new study shows that chemicals with an estrogen effect, like DDT, cause a drop of up to 90% in the plant's ability to attract beneficial soil bacteria with plant estrogens.

If chemicals like DDT are in the soil, these plants may

produce more plant estrogens to try and overcome this reduction and attract bacteria to make "natural fertilizer." This may lead to a change in plants so that they increase their production of phytoestrogens. Evidence from livestock has shown that when they ate these crops they received increased "environmental estrogen" that caused a reduction in their fertility. This may have implications for human populations as well. ■

Here is the ad that was placed in leading newspapers:



Was your mom taking DES?

From 1938 to 1971, DES (diethylstilbestrol) was considered a miracle drug for women experiencing complications with pregnancy. However, it was later discovered that DES contributes to certain health problems in the children of DES mothers and in the women themselves. These children are at increased risk for certain forms of cancer, infertility and other health problems. If you or your mom were exposed to DES, talk to your doctor and call 1-800-DES-9288 for more information.

WE'RE THERE.

For Your Health. For Your Community.

DEPARTMENT OF
HEALTH
Tom Ridge, Governor

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normal “which suggests that the fundamental change is in the underlying structural, i.e. fibromuscular, development of the uterus.” Writing about prematurity, Dr. Haney notes that the rate of premature delivery ranges from 2.6 to 4.7 times higher for DES daughters. Those with a normally shaped uterus still have a greater risk for premature delivery. He cautions about using cerclage on every DES daughter to prevent early delivery, reporting that the vast majority of DES daughters can deliver viable infants. He informs readers that “Some second-trimester losses may occur in DES-exposed women because of incompetent cervixes, while others are the result of premature labor. This is an important distinction, since the therapies employed in these conditions are very different, i.e., cerclage versus pharmacologic suppression of labor.”

“Ectopic (tubal) pregnancy rates for DES daughters range from 3.7 to 8.6 times higher than in unexposed women.”

Ectopic (tubal) pregnancy rates for DES daughters “range from 3.7 to 8.6 times higher than in unexposed women...and “are not associated with a history of pelvic

inflammatory disease (PID)”. As for first-trimester pregnancy loss, he writes that “it has been observed repeatedly in women exposed prenatally to DES, with a relative risk in the range of 1.3 to 4.4.”

Dr. Haney concludes his review with this statement: “Prenatal DES exposure can affect virtually the entire reproductive tract, including the vagina, cervix, uterus, fallopian tubes, ovaries, and mesonephric remnants. DES-related anomalies can affect multiple reproductive functions causing higher rates of spontaneous abortion, premature labor, and ectopic pregnancy. A conservative approach is recommended when treating gynecologic and obstetric problems in this population, since the tissue response to conventional therapy may be different in these women.”

“The preterm prediction study: toward a multiple-market test for spontaneous preterm birth”: by R.L. Goldenberg et al, *American Journal of Obstetrics and Gynecology*, September 2001.

THIS study is of interest to us because DES daughters have a greater risk for preterm birth than do unexposed women. While the women in this study were not identified as to DES status, the risk factors that are described will be of interest to our readers.

A number of potential markers for spontaneous preterm birth were studied. The authors report that the strongest mark-

“Prediction is helpful in that the woman and her doctor are prepared.”

ers—from tests done at 24 weeks—for delivery at less than 32 weeks were:

- a positive cervical-vaginal fetal fibronectin test
- a high percentile rating for a-fetoprotein and for alkaline phosphatase
- a short cervix

Prediction is helpful in that the woman and her doctor are prepared. Other benefits of prediction have not been shown, the authors write, “principally because we have few, if any, effective interventions that can be used once high-risk status has been identified.” ■



Notes from Nora

GOOD news! Thanks to the valiant efforts of our friends Representative Louise Slaughter and Senator Tom Harkin, the Congressional authorization for the National Institutes of Health budget for 2002 includes key DES language. The language in the Appropriations bill reads:

"Diethylstilbestrol—The Committee encourages NIEHS to support research on third generation effects of diethylstilbestrol (DES) exposure, the long-term risks of cancer among DES-exposed daughters and sons, and genetic markers for DES exposure through all available mechanisms, as appropriate."

The NIEHS is the National Institute of Environmental Health Sciences, a branch of the National Institutes of Health. Their DES research is conducted on animal models, and it is important research providing evidence to strengthen the case for further human study. DES research at the NIEHS is led by Retha Newbold, and her talk is one of those included in our 2001 International Colloquium Transcript (see ad in this issue). This Congressional language sends a strong signal that the Congress continues to give priority to DES research, and provides the basis for members of Congress to seek progress reports and monitor how funds in the NIH are spent.

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DES Action's Board

DES Action's Board of Directors held our semi-annual meeting October 12-13 in beautiful Sonoma, CA. These meetings set the direction for program, policy, and fundraising over the course of the year. We held a very productive meeting which included discussion of a re-design of our website—look for a new look soon! The Board also thanked and said goodbye to Andrea Goldstein and Pat Cody, whose terms expired. We re-elected outgoing Board members Molly Spira and Lisa Summers. (Board members are eligible to serve for two three-year terms in a row and then must leave the Board

for at least one year. Andrea and Pat had both served for six years; Molly and Lisa had completed their first three-year terms.) Newly elected to the board are longtime volunteers Nancy Harding, an educator from Pottstown, PA, and Barbara Tunick, a writer from Teaneck, NJ. We welcome our new members, both of whom bring a wealth of experience and talent.

Elections for officers of the organization produced a new roster as well. The officers for the year 2001/2002 are as follows: Molly Spira, President; Mike Freilick, Vice President; Fran Howell, Treasurer; and Karen Fernandes, Secretary. ■

Letters to the Editor

Dear Editor:

As someone who has an interest in perinatal health care, you will want to know about my new book—*The Pregnancy Bed Rest Book*—being released by Berkley/Penguin Putnam in October. This book is a survival guide for expectant mothers and families and covers such topics as: adjusting to horizontal living; coping with hospitalization; making bed rest a family affair; and transitioning to upright living.

My new web site, www.pregnancybedrest.com, complements the book by providing articles, an e-mail support list, updates to resources and links, and book recommendations.

If you'd like to learn more about *The Pregnancy Bed Rest Book* or www.pregnancybedrest.com, please contact me at a-tracy@pregnancybedrest.com.

Amy E. Tracy



DES Action's International Colloquium

April 2, 2001

Washington, D.C.

NOW AVAILABLE!
TRANSCRIPT FROM DES
ACTION'S INTERNATIONAL
COLLOQUIUM

This 65-page transcript from our April 2, 2001 Colloquium is our longest ever! The transcript features presentations from the following experts:

- Retha Newbold, M.S., NIEHS, *Third Generation Research*
- John McLachlan, Ph.D., Tulane Center for Bioenvironmental Research, *What DES Means for Science*
- Arthur Herbst, M.D., Director, Clear Cell Cancer Registry, *DES Cancer Update*
- Kenneth Noller, M.D., *Long-term DES Follow-up Study*
- Candy Tedeschi, RNC, OGNP, DES Screening Clinic, *Caring for DES-exposed individuals*
- Flora van Leeuwen, Ph.D., Netherlands Cancer Institute, *The Risk of Hypospadias in Male Offspring of Women Exposed to DES in Utero*
- Sidney Wolfe, M.D., Health Research Group, *DES as a public health issue*
- Pat Cody, DES Action, *History of DES Action*
- Nora Cody, DES Action, *the National DES Education Campaign*
- Carol Perry, DES Cancer Network, *Coping with Cancer*
- International Roundtable, *Reports from Around the World*

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