

Cancer Risk for DES sons

by Pat Cody

"Cancer risk in men exposed in utero to diethylstilbestrol" by William C. Strohsnitter et al, *Journal of the National Cancer Institute*, April 4, 2001.

A study published in the April 4th issue of the *Journal of the National Cancer Institute* suggests that men may be at increased risk of testicular cancer if they were exposed to DES before birth.

As part of the National Cancer Institute's long-term follow-up study of DES sons, William C. Strohsnitter of Tufts University School of Medicine in Boston, Massachusetts, and colleagues report on 1,354 DES sons and 1,394 non-exposed or "control" men. They found that overall cancer rates among DES-exposed men were similar to those among unexposed men. But they also found that men exposed to DES might be at a threefold increased risk of developing testicular cancer compared with those who were not exposed.

The small numbers of cancer involved—7 testicular cancer cases in the DES-exposed group, and 2 in the non-exposed

group—make it difficult to conclude with certainty whether DES exposure increases the risk of testicular cancer. Study authors point out that the entire increase in testicular cancer is found in one cohort, the Mayo Clinic group, and that therefore it may be due to chance. The increase is also not statistically significant and is limited by its small size.

At the same time, a possible connection between DES and testicular cancer cannot be ruled out and further investigation is definitely needed. In thinking about possible reasons for the increase seen in the Mayo Clinic cohort, Strohsnitter et al note that the men within the Mayo Clinic cohort were exposed to lower DES doses than were the men from the three remaining, and speculate that "An association between prenatal DES exposure and testicular cancer risk could depend on the level of exposure. . . these data suggest that prenatal DES exposure at low doses may be associated with testicular cancer risk." They note that this hypothesis "is consistent with the results of any animal study where prostate abnormalities occurred in mice receiving low but not high DES doses."

The NCI plans to continue to follow this group to try to determine whether a higher risk for testicular cancer is linked to DES exposure. In conclusion, the article states that "The men currently being followed are

approaching the age at which most cancers are diagnosed. Consequently, further follow-up of this population will enable investigators to determine what cancers, if any, are affected by prenatal DES exposure."

Wayne Beyer, M.D.,

of Maryland, a DES son,

in response to the report above, advises sons to do testicular self-exam. Your doctor should be able to demonstrate the proper technique.

Dr. Beyer notes that:

"As with breast exams, the key is to become comfortable with the current state of the organ. What is then important is the presence of any change a month later.

You approach potential skin cancer the same way, breast cancer...Cancer is growing cells, so it is the CHANGE that is relevant.

Also, I don't mean to scare anyone, and there is no data on this re: DES at all, but a self breast exam on a monthly

basis is not a bad idea either.

Breast cancer in men may be related to a family history in the females, so be prudent.

I just had a male cousin come down with it."

I N S I D E

Retha Newbold

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Update on DES Internet Listservs

by Sally Keely (aka "DESxposed")

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 owner-DAL@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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Belgium
Canada
England
France
Ireland
The Netherlands
New Zealand

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Effects of DES & Other Environmental Estrogens in Experimental Animal Models

Summary of a presentation by Retha Newbold, Head, Developmental Endocrinology Section, Laboratory of Toxicology, National Institute for Environmental Health Sciences

ON April 2, 2001, we held our International Colloquium, a daylong conference with presentations from leading scientists and clinicians and participation from DES Action groups around the world. In this issue of the VOICE we feature the presentation by Retha Newbold, a pioneering scientist studying the effects of DES on mice. Ms. Newbold recently published important reports on increases in reproductive cancers in the offspring of "DES daughter" mice, and in 1999 we presented her with our Distinguished Service Award. Her entire presentation, along with the others from the Colloquium, will be transcribed and published. Watch this newsletter and our website (www.desaction.org) for a publication announcement.

Retha began by describing "The Fragile Fetus," a phrase coined by fellow DES scientist Howard Bern. She made these essential points:

- The DES experience dispelled the scientific concept of the placenta as an impenetrable barrier.
- The developing organism is extremely sensitive to perturbation by chemicals with estrogenic or endocrine-disrupting activity.
- Exposure to chemicals such as DES during critical stages

of genital tract differentiation may have permanent long lasting consequences.

- These consequences may not be expressed or detected until later in life.

The DES-exposed experimental mouse is a valid model to study human disease, and has replicated and predicted many lesions observed in DES-exposed humans. Some examples include vaginal adenosis and adenocarcinoma in females, and retained testes and structural genital

increases in reproductive tract tumors in both male and female offspring whose grandmothers had taken DES. She explained that prenatal exposure to DES delays the expression of Hox genes, which are genes involved in the structural differentiation of the reproductive tract. Scientists still do not know how DES effects are transmitted to the third generation, and studies are underway to examine the mechanisms involved in this transgenerational event. Whether these multigenerational

B. Oviduct Malformations



Control



DES

abnormalities in males. The illustration on this page shows the formation of the mouse oviduct in control (unexposed) mice and DES-exposed mice. The oviduct in the mouse roughly corresponds to the fallopian tube in the human. As you can see, the oviduct of the DES-exposed mouse is grossly malformed by the DES exposure.

Retha's research on third generation effects in mice (VOICE #78, #85) showed

effects will also occur in humans is currently unknown.

Newbold also raised the important and provocative question: do other estrogenic chemicals that are similar to DES cause adverse effects at the levels of exposure that exist in the environment? This issue, which is discussed thoroughly in the book *Our Stolen Future*, among others, is one which should command the attention of every public health and regulatory agency in the country. ■

Medical Reports

by Pat Cody

"LONG-TERM cancer risk in women given diethylstilbestrol (DES) during pregnancy," by L. Titus-Ernstoff et al. *British Journal of Cancer* (2001) 84(1), pp. 126-133.

This article confirms earlier studies showing that DES mothers have a higher risk for breast cancer than do non-exposed mothers. The report summarizes questionnaires returned by 2,019 DES mothers and 1,978 unexposed mothers whose records on exposure came from a number of medical centers.

The researchers found a 27% greater risk for breast cancer among the DES mothers. The development of breast cancer in the DES-exposed cohort was not related to any family history of breast cancer or to any use of oral contraception or hormone replacement treatment. The good news in the study was that they found no association between DES use during pregnancy and risks for ovarian, endometrial or other cancers.

23 YEARS OF

DES
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S E R V I C E

Notes from Nora

International DES Colloquium a Big Success

ON April 1 and 2, DES-exposed women from around the world convened in Washington, D.C., for DES Action's International Colloquium. DES Action USA invited DES Action affiliates from Australia, Canada, England, France, Ireland, and the Netherlands to join us for several days of meetings and activities. We emerged with greater energy and more determination than ever to make a difference in each country.

The excitement was palpable as we gathered on Sunday morning, April 1st, with most of us meeting one another for the first time. We learned that DES Action groups in Europe and Australia have accomplished a great deal in the face of resistance and denial from their governments.

In Australia there are two DES support groups, one in New South Wales (near Sydney) and one in Melbourne. Each has worked hard to garner publicity and to persevere against great obstacles. Over the years the Australian health ministry has talked about programs and then never delivered them. Recently the Health Minister stated that "the Department considers that a general publicity campaign for DES exposed people to identify themselves would create anxiety without tangible benefit." This is what the founders of DES Action USA were told when they appealed to our government,

and this attitude is what led to the establishment of DES Action.

Undaunted, the Australian groups have managed to get quite a bit of media coverage, leading to many requests for information from DES-exposed women there.

DES Action Canada is a well-established, strong organization with many publications on

"Representative Slaughter spoke about her shock at learning that DES was banned in poultry in 1959 but given to pregnant women into the 1970s, and never banned for use in humans."

topics such as direct-to-consumer advertising and the ethics of accepting contributions from pharmaceutical companies (like DES Action USA, they do not accept such contributions). In Canada most nonprofits are supported by the government, and DES Action Canada receives such support as well as support from their members.

This spring DES Action Canada will be starting a new project on the links between DES and endocrine disruptors.

We received good news from England: the Royal College of Obstetrics and Gynecology is developing a protocol for ob/gyns based on the materials emerging from the U.S. Centers for Disease Control's National DES Education Program. DES Action/UK is supporting the first

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lawsuits filed by clear cell cancer survivors. The legal system throughout Europe has little provision for DES lawsuits. There is very little product liability law and there are no contingency fee arrangements for attorneys, which means that DES daughters must pay lawyers by the hour to even begin a legal action.

In France, the peak years for DES usage were 1968-1971, so the DES daughters and sons are younger as a group than the population here in the U.S. There are a number of women with clear cell cancer who are pursuing legal action in the French courts. DES Action France, with a small budget and dedicated volunteers, works hard to offer resources and help to the DES-exposed in the country.

Two delegates from Ireland spoke about the difference of living in a small country: all DES daughters go to the same doctor at a DES clinic in Dublin. Dr. Mary Wingfield is well-informed and serves as an excellent spokesperson to explain the effects of DES to the media. In the week following the Colloquium a leading Irish newspaper and radio station featured articles and stories about DES, including an interview with Dr. Wingfield.

In The Netherlands, DES Centrum (DES Center) is a well-established group that has been operating since 1982. They regularly speak to various groups and to doctors and nurses in hospitals and clinics. In addition, there is a network of about 100 health care providers who care for DES-exposed individuals and



At our Colloquium, Program Director Pat Cody, Executive Director Nora Cody, Representative Louise Slaughter, DES Action President Kari Christianson.

hold an annual workshop to keep themselves up to date about DES treatment.

DES Centrum has also reached a settlement with Dutch pharmaceutical companies and there is now a fund of \$35 million to be divided by 18,000 DES daughters and mothers who have registered. They are now in the process of establishing settlement amounts for various health outcomes. The amounts to be distributed to each individual are expected to be quite small by U.S. standards, but high by Dutch standards since under their law it is nearly impossible to sue a drug manufacturer.

There is very little DES research overseas and the women and men in other countries rely heavily on the United States for research to answer their questions. We made this point to lawmakers when we took women from foreign countries around to meet with Congressional staff on Tuesday, April 3. We explained why continued funding for DES

research and education was essential for DES-exposed people around the world, and for the scientific lessons DES imparts.

On Monday, April 2 close to 100 people attended the International Colloquium, where we heard from three panels of distinguished speakers. The day afforded opportunities for DES-exposed people to meet one another and to ask questions of the panelists. Following the panels, we held a reception with special guest speaker Representative Louise Slaughter. Representative Slaughter spoke about her shock at learning that DES was banned in poultry in 1959 but given to pregnant women into the 1970s, and never banned for use in humans. She thanked DES Action for our work and reiterated her strong commitment to DES research and education.

A full transcript of the Colloquium will be available soon. Watch this newsletter and our website for the publication announcement.

Tort Reform—Again!

By Pat Cody

MANUFACTURERS, especially drug companies, have been working for many years to make it harder for consumers to get compensation for injuries caused by their products. This kind of lawsuit is a civil suit, not criminal, and such injuries are defined legally as “torts.” Product liability law at present is state law and varies from state to state. Some states, including California, Florida, Michigan, New York, Washington and Wisconsin, have legislation—inspired by the DES lawsuits—that allows legal action to go forward even if the plaintiff cannot name the maker of the injurious product. This is often the case with DES daughters who want to sue for cancer, infertility, and unfavorable reproductive outcomes.

“Tort reform” is the slogan for manufacturers who want a federal law that would in effect replace existing state laws. This “reform” weakens our rights to our day in court in a number of ways. Injured consumers would need to name the manufacturer, “caps” or ceilings would be set on punitive damages—which can at present be ordered to deter irresponsible manufacturing of harmful products. While such awards are few, the possibility of this outcome does send a message to any company that fails to consider consumer health and welfare.

More importantly from our point of view, the tort reform bills being presented in Congress right now may include establishing a “statute of repose” that

would ban filing any suits against a company after more than 18 years from the purchase of the product... This would be devastating to those of the DES community whose injuries may only show up 20-30-40 or more years after the drug was sold to the plaintiff’s mother.

Last year the House of Representatives narrowly approved “tort reform” but in the Senate a tight schedule and a threatened

“Nothing will ever compensate me for what I’ve lost. However, those who have caused my pain must be held accountable for their actions. They realized the profits from the sale of DES; they must also bear the responsibility...”

filibuster from the Democrats meant that no hearings were held, so the measures died. George Bush made tort reform part of his platform, whereas Clinton vetoed the one bill that did pass both houses in 1996. In the present, more conservative, spirit in Washington, Democratic Sen. Joe Lieberman has agreed to be one of the leading sponsors of the latest attempt to weaken consumer protection. Democratic opposition in the past has defeated these bills, but we are in different times. Now more than ever, consumers need to let their Senators and Representatives know about how the “tort reform” bills damage the health and safety of all of us.

DES daughter Stephanie Kanarek testified in Congress four years ago about a similar law. Her eloquent words are as

fitting as ever:

“Let me emphasize—I have a handicapped daughter because the pharmaceutical companies ignored evidence that told them not to market this chemical for use in pregnancy.

“Why would you protect the wrongdoer at my expense? Nothing will ever compensate me for what I’ve lost. However, those who have caused my pain must be held accountable for their actions. They realized the profits from the sale of DES; they must also bear the responsibility... The manufacturer must be sent a loud, strong message that, as a society, we will not tolerate such a callous disregard for the health of our mothers, wives and daughters.”

These “tort reform” bills are in Congress now, so it is important to send a letter to your Representative and Senators.

As we suggested back in 1997, the essential elements of a letter, which ideally should include your own story in your own words, should be something like this:

“I urge you to vote “no” on “tort reform.”

Consumers should keep the right to seek compensation for their losses. The provisions of “tort reform” legislation being proposed would unfairly restrict consumer access to the courts and will lead to more unsafe products.

“DES is an FDA-approved drug that should never have been given to pregnant women. This cancer-causing drug was not fully tested and laboratory tests indicating its toxicity were ignored. The story of DES is a classic story of profits before people. You as the people’s representative must help us prevent another DES.” ■

DES Stories: *Faces and Voices of People Exposed to Diethylstilbestrol* is a photo essay by Margaret Lee Braun, one of the founders of the DES Cancer Network, and photographer Nancy Stuart of the College of Imaging Arts and Sciences at the Rochester Institute of Technology. This book effectively combines 40 portraits of DES mothers, daughters and sons—alone or with their families—with a description of their DES exposure, and their heartfelt statements about how DES affected their lives. It is available from DES Stories, Box 10114, Rochester NY 14618 for \$24.95, plus \$3.50 shipping.



DES daughter, Jennifer Little-Moore, with daughters Miranda and Mae-Mae. Exposed 1961

I was trying to get pregnant after Miranda's birth and it wasn't happening. I started bleeding, but my Pap smears kept coming back normal. I instinctively felt that something was wrong. I demanded a colposcopy and when the doctor looked through the scope, he went ahead and did a tissue biopsy and a cone biopsy.

I asked if the cancer could be related to DES, and all of the doctors said no. It wasn't a DES cancer. It was garden-variety squamous cell cervical cancer. It's possible that my infertility and cancer have nothing to do with DES. I don't know.

Having cancer profoundly changed me. I would never want to go through it, but I think it changed me for the better. Now I know I can make it through these things. They are really powerful teachers. It kicked me out of my life into a new one. I realized the perfect life I was trying to attain was an illusion. It's like the Chinese proverb, "My roof is falling. Now I can see the moon."

Jennifer started having gynecologic exams at 21, and her doctor found DES-related adenosis. After marriage, Jennifer had difficulty becoming pregnant, and tried a cycle of infertility treatments. When she became pregnant, she had an exam every two weeks until baby Miranda was born at full term.

Soon after Miranda's birth, Jennifer's doctor told her, incorrectly, that she didn't need DES exams any more because only younger women needed to be checked for DES cancer. Jennifer was 31. She was relieved because she did not have insurance to cover the colposcopy exam.

Two years later Jennifer was diagnosed with invasive cervical cancer. She had a radical hysterectomy and her uterus, fallopian tubes, and top of vagina were removed. During her recovery she and her husband began the process of adopting nine-month old Mae-Mae from China. Jennifer is an art teacher. After separating from her husband, she is raising her girls as a single mother.

I still deal with anxiety. I keep some distance from DES stuff. There's just much medical information I can tolerate. What I do is make sure I get the best possible health checkups.

After my surgery I was afraid I couldn't adopt because of the cancer. One day I called the DES Cancer Network and talked to a woman who said, "You know, a lot of DES daughters are adopting gorgeous little girls from China." When she said that, my heart leapt. I knew right away China was the right place.

I feel like these are daughters I'm supposed to have, which isn't to say that any of these things should have happened. The way DES was promoted was inhumane. It's like the promotion of tobacco, baby formula, or bovine growth hormone in milk. But when my roof fell in, I found a more interesting reality. I think about it when I look into the faces of my daughters. I can see the moon, and it is beautiful.

—Jennifer Little-Moore

Book Notes

Rose's Colors: A Mother's Journey by Elizabeth Levine Wandelmaier. 2001. \$16.00 paperback or \$8.00 as e-book from www.Xlibris.com. Also available from Amazon.com.

ROSE is the severely disabled daughter of Elizabeth and Roy Wandelmaier, born 8 weeks prematurely to writer, painter and DES daughter Elizabeth. This is a wonderfully written and poignant story of the first



eight years of Rose's life, her progression to speech and understanding. Elizabeth kept a journal of

their experiences from the first terrible knowledge of Roses' handicaps through a life of heroic patience as she and Roy struggle to help Rose achieve a meaningful life.

Elizabeth reached beyond her own life as so many DES-exposed people have, to establish the DES Third Generation Network as an advocacy and support group to work for more research on our third generation (Box 21, Mahwah NJ 07430. DES3gen@aol.com.) She is also a member of the Board of DES Action.

THE Health Research Group of Public Citizen has published the latest edition of *20,125 Questionable Doctors*. It is a listing by 18 regions of physicians who have been sanctioned by their

state medical boards. This valuable report covers doctors who were disciplined from January 1990 through December 1999. Almost all of the actions were for serious offenses but less than half had serious consequences. Most of the doctors disciplined for the most serious offenses: sexual abuse or misconduct, substandard care, incompetence or negligence, criminal conviction, mis-prescribing or over-prescribing, or substance abuse, were not required to stop practicing.

This would be a good book for your library to have. Each regional edition is \$23.50 and can be ordered either by phone (1-877-747-1616) or from the web site www.questionabledoctors.org

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