

New Research Raises Concerns about Third Generation Impact of Des Exposure

by Fran Howell, Board of Directors, DES Action

RESULTS of a new study should give pause to those who have been exposed to DES, and to researchers who are studying its effects.

The findings, published in the March 30, 2002 edition of the prestigious British medical journal *The Lancet*, show that male children of women exposed prenatally to DES have a greater risk for the birth defect hypospadias than the general population.

While studies in mice have indicated the possibility of problems for children of DES daughters, this is the first evidence we have of human transgenerational effects of DES exposure on the so-called "third-generation."

The study was done by the Netherlands Cancer Institute. After learning of higher than normal rates of hypospadias reported by the Netherlands DES Information Centre, scientists at the Cancer Institute decided to conduct a larger study. When researcher Dr. Flora van Leeuwen and her team examined birth records of more than 8,000 boys born through fertility centers, they

found a DES connection. The results: among 8,729 boys whose mothers were not exposed to DES, 8 cases of hypospadias were reported. For the 205 mothers prenatally exposed to DES, there were 4 cases of hypospadias. **The findings represent a more than 20-fold increased risk for the DES-exposed group.**

Hypospadias is a benign (non-cancerous) birth defect in which the urethral opening on the penis is in the wrong place. This quote from Sandra Steingraber's book *Having Faith* (reviewed in this issue) explains hypospadias more thoroughly.

"Like neural tube defects, hypospadias happens when a strip of flat tissue fails to roll up to form a closed tube. In this case, the tube is the male urethra, which runs down the middle of the penis and so connects the bladder to the outside world. If the urethral tube does not fuse completely, the external opening will emerge somewhere along the shaft of the penis instead of at the tip...many such anomalies are reparable with surgery."

Leaders of DES Action are urging more research. As Program Director and founder Pat Cody states, "What we don't know is why there is more hypospadias in sons of DES daughters. Researchers must look into it. DES Action is calling for further studies, at both the molecular and cellular levels, to determine how and why this third generation effect

is occurring," Cody says. "We also question whether DES is affecting third generation sons and daughters in other ways too. We hope this study finally draws attention to the urgent need for more research."

One area of interest to scientists is the impact of chemicals in our environment. DES is similar to other chemicals known as endocrine disruptors, so if exposure can harm not only one generation, but others to come, then the results of this study may have broad implications which reach far beyond the DES exposed population.

"Investigations into how DES affects people, and their families through generations may ultimately unlock all sorts of environmental pollution mysteries," says Cody. "If problems for the DES population aren't enough to interest scientists, the huge ramifications of environmental toxins should do it."

The best place to start is the National Cancer Institute. The NCI has identified known DES exposed women and men, along with a control group.

According to Cody, "this is an opportunity that shouldn't go to waste. We urge the NCI to increase funding for this important research into potential effects of DES exposure on our third generation of boys and girls. By so doing, we could learn more about how the chemicals in our environment are affecting us all." ■

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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 e-mail to des-sons-subscribe@yahoogroups.com. The website for the sons' network is <http://groups.yahoo.com/group/des-sons>.

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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Notes from Nora

In this issue we report on two recent studies concerning multi-generational DES effects. The front-page article about increased risk for hypospadias in DES grandsons describes an important and disturbing study that appears to provide the first evidence of a DES effect on the generation not directly exposed: the grandchildren. DES sons themselves also have an increased risk for hypospadias. We do not know if there are any other adverse health effects in either male or female third generation offspring, because no one has looked yet.

This is a key point: researchers have not yet delved into all the possible health effects that might occur in the third generation. This is a huge task, requiring large groups of cooperative patients with identified DES exposure, and lots of money. One place to start is the most obvious, and the path that's been taken so far. That is, to look for replication of effects already seen in the second generation. The researchers at the Netherlands Cancer Institute did just that, and found the increased risk for hypospadias.

Using a very small sample group, doctors at Baylor College of Medicine also looked for replication of DES effects in the lower genital tract, this time in a group of young women born to DES daughters. They didn't find any effects, and chose to use this data to reassure the public that "on the basis of preliminary

findings, it is probably unlikely that any significant abnormalities will be seen in third-generation daughters." In my opinion, this is a very sweeping and misleading statement to make based on one

"This is a key point: researchers have not yet delved into all the possible health effects that might occur in the third generation."

small finding. While I hope the Baylor physicians are correct, I would not want for this study to be used to minimize the need for more third generation research.

As many readers know, the National Cancer Institute is currently conducting a long-term follow-up study of DES mothers, daughters, sons, and now grandchildren as well. The cohort they have established can be used as a base for the future studies that are needed, both to verify or refute the hypospadias link and to explore other potential effects. As I write this, I am making arrangements for DES Third Generation Network co-chair Elizabeth Wandelmaier to attend the Steering Committee overseeing DES research at the NCI. She will be a strong voice advocating that the necessary resources be put into more third generation research. We owe it not only to all the DES-exposed families, but

to a world that still has much to learn about chemicals like DES. Stay tuned to this newsletter and my letters for a report on this meeting and on progress in DES research.

DES has sometimes been grouped with other chemical substances that interfere with the body's endocrine system and are thus called endocrine disruptors. DES Action has joined with biologists, public health activists, environmentalists, and others in calling for much stricter limits on chemical production and pollution and more thorough testing of chemicals widely used for their potential to cause long-term reproductive and other health damage.

This movement, linking environmental and health concerns, is growing in size and scope. Sandra Steingraber's new book *Having Faith* (reviewed in this issue) discusses chemical pollutants and their effect on pregnancy and the fetus. We are encouraged by the growing attention to this issue, but there is still so much work to be done. That's why DES Action formed a new Endocrine Disruptors Committee at our Spring Board of Directors meeting. We'll be looking for ways to network and join forces with those who share our concerns, and ways to advance an agenda for cleaner water, food, and air for all of us.

Book Review:

Reviewed by Pat Cody

Having Faith, by Sandra Steingraber. Perseus Publishing, 2001. 342 pp. \$26.00

"**HAVING FAITH:** An Ecologist's Journey to Motherhood" is a wonderfully poetic book interweaving Dr. Steingraber's personal experience with her insights on the pregnant woman and her environment. The first nine chapters take us through each month of pregnancy with its changes, and her observations. Chapter 10 is on breast feeding and the final two chapters inform us of the perils of breast milk, and the summary of her argument on what needs to be done and where to start.

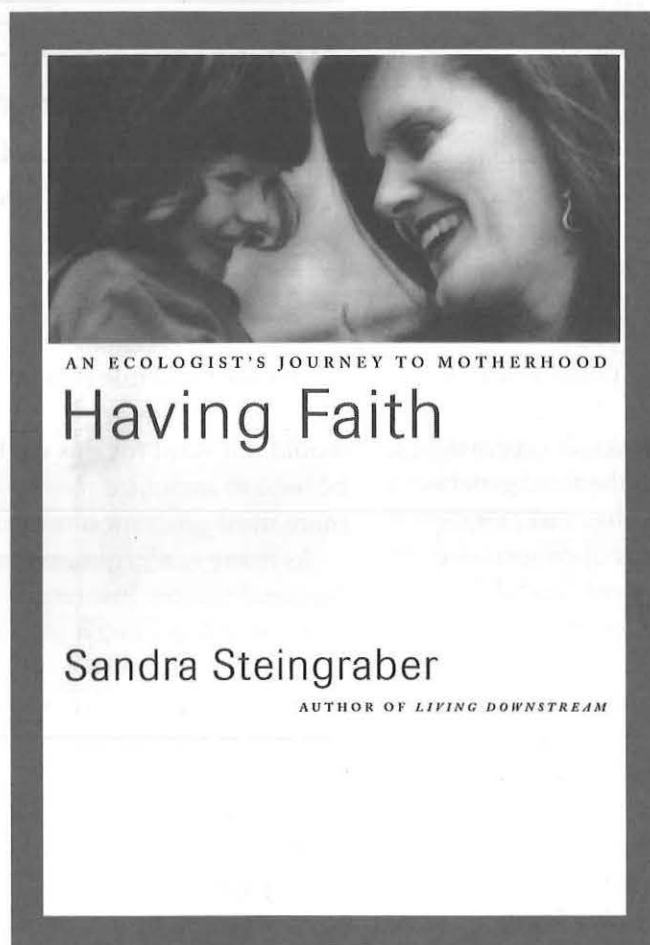
Her chapters are labeled for the moons, and her sixth month, June, is Rose Moon. Here she makes real the pollution dangers in the environment that can affect her child:

"Not a single one of these pregnancy magazines encourages mothers to find out what the Toxics Release Inventory shows for their own communities... I looked it up on the Internet... McLean County is one of the top counties in Illinois for airborne releases of reproductive poisons. The biggest emissions of fetal toxicants are hexane from the soybean processing plant and toluene from the auto plant. My list also includes glycol ethers and xylene. All are solvents.

"I also found out that the university (where she works) uses six different pesticides on their grounds and fields. So I looked up their toxicology

profiles. Two of them are known to cause birth defects in animals... I'm wondering why our obstetrician never talked with us about these kinds of issues. Or about the problems Bloomington

Steingraber does her best to bring scientific studies from many countries and about many chemicals into the discussion, as well as historic notes on earlier childbirth beliefs and practices.



has had with its drinking water... Why is there no public conversation about environmental threats to pregnancy?... Thirty-four million pounds of reproductive toxicants were released from Illinois industries last year (1997). How would you make that number meaningful to people?"

When she moves into the chapter on breastfeeding, she presents dismaying data on the increasing presence of pollutants in breast milk. Switching to formula is no solution: breast milk has many advantages, and formula is usually mixed with polluted tap water. It's clear, however, what

continued on page 6...

Breast cancer and HRT more strongly linked

WE know that DES mothers have an increased risk (about 30%) for breast cancer. DES daughters naturally wonder whether their in utero exposure to DES might also affect their risk for breast cancer. So far, this question has not been answered, and more research is needed as DES daughters age and reach the stages of life where breast cancer risk is higher.

A recent study has reinforced the link between breast cancer and another type of hormone exposure: menopausal hormone replacement therapy (HRT). This study should give pause to all women, but especially to DES-exposed women contemplating or taking HRT.

In the February 13 issue of the *Journal of the American Medical Association*, Dr. Emily White and colleagues at the Fred

Hutchinson Research Center in Seattle reported significant increases in breast cancer risk for HRT users. Specifically, they studied 705 post-menopausal women (aged 50-74) who developed primary invasive breast cancer and 692 matched controls. They found a threefold increase in the risk of lobular carcinoma for women with a recent history of five years or more of use of HRT, and a fourfold rise if the women used combination therapy (i.e. estrogen plus progestin).

For nonlobular breast cancer, primarily ductal, the risk rose about 50% among HRT users. Researchers estimated that in a given year, nonusers of HRT would have an incidence of 253 cases of breast cancer per 100,000, compared with 419 per 100,000 for women with five

years of recent HRT use. The bottom line: when investigators looked at all types of breast cancer, they found an increased incidence of 60-85% for HRT users, depending on whether estrogen alone or a combination of estrogen and progestin was used.

One weakness of the study was that the women themselves decided whether to take hormones, rather than being assigned to take either drugs or a placebo. A large-scale study called the Women's Health Initiative, in which women have been assigned at random to take either hormones or a placebo, is under way at the National Institutes of Health. This study should provide more definitive answers, but results are not expected until 2004 or 2005.

Book Notice:

By Amy Allina

The Truth About Hormone Replacement Therapy

THE National Women's Health Network is excited to announce that our new book, *The Truth About Hormone Replacement Therapy: How to Break Free From the Medical Myths of Menopause*, is now available.

More and more questions are being raised about the efficacy and safety of hormone replacement therapy. This book contains a wealth of accessible and thor-

oughly referenced information not available elsewhere. Besides a balanced presentation of the risks and benefits of hormone therapy, it also reviews alternative treatments for menopause symptoms, including herbs, phytoestrogens, and "natural" hormones.

Buy your copy today from a bookstore or from the National Women's Health Network website, www.womenshealthnetwork.org/clearinghouse/thwh.htm. The cost is \$15.95 (\$10.95 for NWHN members), plus a \$4 shipping charge. If you don't have online access, you can also order the book by calling the National Women's Health Network at 202-347-1140.

Menopause: A Series of Articles from the DES Action Voice

THIS small booklet, available for \$8.00, includes 12 articles from the DES Action Voice about menopause, the pros and cons of HRT, and alternative treatments. The booklet is divided into four sections: Menopause & After; Alternative Views & Remedies; Hormone Replacement; and Estrogen and Breast Cancer. If you are interested in receiving a copy, send us a check for \$8.00 with your name and address.

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the next steps must be:

"So let's look at political action as an alternative approach to purifying breast milk.

"Not a single one of these pregnancy magazines encourages mothers to find out what the Toxics Release Inventory shows for their own communities."

All the biological evidence indicates that it works. The dramatic declines in certain key breast milk contaminants from the 1970s to the turn of the twenty-first century are a direct consequence of DDT-style bans, tighter regulations, incinerator closings, emission reductions, permit denials, right-to-know laws, recycling initiatives, and tough environmental enforcement at both local and national levels."

Steingraber cites reports from breast milk researchers in the

U.S., Germany, Sweden and the Netherlands accounting for these successes. She says that nursing mothers owe a debt not only to public health workers. Scientists, policymakers, but also "plain ordinary folks who cared enough to organize, agitate, write letters, publish articles...sign petitions, march in the streets, stage sit-ins, and generally raise awareness about toxic chemicals... The way we repay this debt—and continue the process of detoxification—is to continue the struggle."

"We also need to insist that breastfeeding is a sacrament of motherhood that cannot be reduced to a risk/benefit equation—even if we did have all the data to create one. By placing breastfeeding in a human rights context, we avoid stultifying breast vs. bottle discussions that urge us to either shut up and nurse or switch to formula if we're so worried about toxic chemicals."

As an ecologist, Dr. Steingraber makes plain that the mother's body is the first environment for her child, one that

she must do her best to enhance and protect. Her combination of biology, clear poetic writing, and an over-arching knowledge based on her own experience provides insights that I can compare to Rachel Carson's *Silent Spring*. Everyone can learn from this important book. ■

Letters to the Editor

Editor:

Thank you for sending me the article on Forteo (Voice, #90). I am glad someone is actually paying attention to this drug!

However, there is a small error in the article that you may or may not wish to correct. In the next to last paragraph, it quotes me as saying the fractures were "symptomatic." That should read "asymptomatic." Take care and keep in touch.

Peter Lurie, MD, MPA
Deputy Director,
Public Citizen's Health
Research Group

Don't Accept Denials of Care Encouraging news from New York state

In a recent letter to the New York Times, New York State attorney general Eliot L. Spitzer encouraged consumers to challenge their health plan's denials of care. He noted that most people don't do this because they believe they have little hope of succeeding, but in fact the majority of New Yorkers who file appeals of denials of care win reversals.

If you feel you have a case and wish to challenge your health plan's denial of care to you, contact your state's attorney general.

TAKE ADVANTAGE OF US!

All of our readers should be aware of the benefits of membership in DES Action and the ways you can take advantage of our services. We are here to serve you, and to further the needs of the DES community.

Here are some of the benefits we offer, in addition to this newsletter:

- Toll-free telephone assistance at 1-800-DES-9288. If we're out of the office, do leave a message and let us know if you need us to mail you something or if you prefer that we call you back.
- Health care provider referral lists, organized by state (except in California, which is by county). We are happy to send you a copy of our list of referrals to health care providers in one state or several.
- Attorney referral list—contact us for referrals to attorneys who handle DES lawsuits.
- Publications—we have many publications dealing with different aspects of DES exposure, including all of the back issues of our newsletter. Contact us for a copy of our publication list and order form.
- Website at www.desaction.org for our members who are online. The website has comprehensive information on DES and its health effects, as well as links to many useful resources and organizations.

Then there are the less tangible, but perhaps even more important, services we provide. These include:

- Advocacy for DES research funds and for DES as an important issue in our nation's health agencies.
- Advocacy for DES education directed at the public and our health care providers—resulting in the current program by the Centers for Disease Control, CDC's DES Update.
- We serve as the voice for the DES-exposed community in the decision-making bodies guiding research and education at the National Institutes of Health and the Centers for Disease Control and Prevention.
- Working to prevent the re-occurrence of similar public health tragedies, like through our work in the Prevention First Coalition.
- Collaborating with like-minded organizations, such as environmental groups, to urge greater caution and testing of chemicals, pesticides, and other hazards that threaten our health and the health of future generations.

Small survey of DES granddaughters reveals no changes

IN a small sample of 28 female offspring born to 26 DES daughters, Dr. Raymond Kaufman and Dr. Ervin Adam from the Baylor College of Medicine looked for gynecologic changes typically seen in DES daughters. Each of the 28 young women, all over the age of 18, underwent a pelvic exam and provided a detailed medical history. Their study was reported in the February issue of the *Journal Obstetrics & Gynecology*.

16 of the DES daughters (i.e. the mothers of the young women examined) had structural changes of the cervix, upper vagina, or vaginal epithelial changes including adenosis. None of the third generation women examined had any changes associated with DES exposure, the researchers found. "Although the numbers are small, the striking differences in findings of lower genital tract abnormalities between mothers and their offspring suggests that

the multigenerational effect of DES observed in mice is likely to be dramatically lower in humans, if present at all," Drs. Kaufman and Adams said.

No hysterosalpingograms—exams which would determine other structural changes (such as uterine abnormalities)—were administered. It should also be noted that the multigenerational DES effects observed in mice were reproductive tumors that occurred later in life, not lower genital tract abnormalities. ■

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