

Survey on Psychosexual Characteristics of DES Daughters and Sons

Reviewed by Pat Cody

LINDA TITUS-ERNSTOFF et al, "Psychosexual characteristics of men and women exposed prenatally to diethylstilbestrol," *Journal of Epidemiology* March 2003.

While earlier large studies of DES exposure have revealed such health effects as cancer, reproductive problems, and immune system impairment, up to now we have not had research on whether or not there are psychosexual outcomes. The present studies being done at major medical centers with National Cancer Institute funding provided an opportunity to look at whether prenatal estrogen exposure influenced sexual behavior.

"Ninety-five percent of women and of men, whether DES exposed or not, reported exclusively heterosexual partners. One per cent of all the respondents, exposed or not, reported 'mostly same sex.'"

Completed questionnaires were received from 3,946 DES daughters and 1,761 unexposed women (controls), and from 1,343 sons and 1,358 males controls.

Ninety-five percent of women and of men, whether DES exposed or not, reported exclusively heterosexual partners. One per cent of all the respondents, exposed or not, reported "mostly same sex."

As for possible psychological effects, these questions were only on the surveys for women. They showed sixteen per cent of DES daughters and seventeen per cent of non-exposed controls reported having been diagnosed and treated for mental illness. For both the DES daughters and the un-exposed women, the statistics are similar: depression accounts

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More Studies on HRT

By Pat Cody

LAST summer we reported on four research studies linking Hormone Replacement Therapy (HRT) to cancer and heart

disease. Our Fall issue carried an article on harmful effects of HRT on women past menopause who already had heart problems. The HRT raised their risks for heart attacks, stroke, and death.

Now we have two additional negative accounts. The March 19 issue of the *Journal of the American Medical Association (JAMA)* reports an increase in invasive lobular breast cancer of 65% in the twelve years from 1987-1999. The more common

ductal breast cancer rose very little during those years. While this study of 190,458 women with breast cancer did not screen for hormone use, the researchers believe that the sharp rise in lobular cancer occurred at a time of increasing HRT prescription.

The second report appears in the *New England Journal of Medicine* for May 8, 2003, but was released on March 17 because the editors thought it was

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How to Join the DES Daughters Listserv

DES Daughters should check out DES-L, the DES daughters listserv 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 1,000 other DES daughters! Note: this list is operated independently from DES Action.



Yes—I want to get answers about DES. Enclosed is my membership.

All members receive *The DES Action Voice* quarterly. Those at the \$100 level and above receive an annual report on DES Action's work and progress. All contributions are tax deductible.

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

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On The Cutting Edge:

An Interview with Davis Baltz Part Two

by Nora Cody

In the last issue of this newsletter we featured Part One of On the Cutting Edge, An Interview with Davis Baltz. Davis Baltz is an environmental and health activist who works for the nonprofit organization Commonweal. Here is Part Two of the interview, conducted by Nora Cody in January, 2003.

Now tell me about Health Care Without Harm. What is it? Are there chapters in every state?

Founded in 1996 at Commonweal, Health Care Without Harm (HCWH) is now an international coalition of 372 organizations in 42 countries whose mission is "to transform the health care industry so it is no longer a source of environmental harm by eliminating pollution in health care practices without compromising safety or care."

The campaign resonates because healthcare professionals take an oath to "first, do no harm," yet the healthcare industry is a source of avoidable public health threats. We believe there is an ethical imperative for the healthcare industry to promote healing in a manner that is as environmentally sustainable as possible.

The campaign promotes comprehensive pollution prevention practices; supports the development and use of environmentally safe materials, technology and products; and educates

and informs health care institutions, providers, workers, consumers, and all affected constituencies about the environmental and public health impacts of the health care industry and solutions to its problems.

Health Care Without Harm's website at www.noharm.org can provide much more detail on our work.

Last spring Commonweal initiated the Collaborative on Health and the Environment, or CHE. DES Action and many other organizations and individuals have joined this new Collaborative. Can you tell me about the goals of CHE and what Commonweal hopes to accomplish in this effort?

The Collaborative on Health and the Environment (CHE) is a new network of concerned people and organizations working together toward the shared goal of improving public and individual health. CHE Partners include representatives of patient organizations, health professional and scientific societies, community organizations, environmental health advocates, and funders.

Chronic diseases and disabilities have reached epidemic proportions in the United States. Asthma, autism, birth defects, cancers, developmental disabilities, diabetes, endometriosis, infertility, Parkinson's disease

and other diseases and disabilities are causing increased suffering and concern.

Scientific evidence increasingly indicates a relationship between a range of environmental factors and these diseases and conditions. One important contributor may be increased exposure to the wide array of chemical substances that are used in modern industrial society.

These pollutants have become widespread in our air, water, soil, food, homes, schools, and workplaces, and thus also in our bodies. Low-income communities and communities of color often bear a disproportionate burden of health risks from such environmental contamination. The developing human fetus appears to be uniquely at risk of harm from environmental toxicants, and such damage can be profound and permanent.

There is significant scientific evidence that environmental factors are important contributors to disease and developmental disabilities, even as understanding of risk varies widely among individual toxicants and diseases. Many cases of some diseases and developmental disabilities could likely be prevented if exposure to contributory environmental factors were eliminated.

Some strategies for prevention are well known, but more resources need to be devoted to prevention research and practice.

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Notes from Nora

DES has been in the news a lot lately, thanks to the hard work of DES Action volunteers and staff who have been collaborating with Centers for Disease Control staff working on the CDC's DES Update. In March CDC's Marsha Vanderford appeared live on CNN (television) to announce the launch of the DES Update. In April we were pleased to see lengthy articles in *USA Today* and the *Boston Globe* newspapers. Also in April, a local television news program in Reno, Nevada featured an interview with a DES daughter. The word is getting out!

THANKS to all the members who took the time to respond to our Survey printed in the last issue. The responses we received were very illuminating and will help shape the organization's work in the coming period of time. I promised a summary of the results, so here it is. If your specific response is not included, have no fear—we are paying close attention to each and every survey we received and we will be acting on your suggestions and good ideas.

Two-thirds of our respondents were DES daughters, one-third were DES mothers, and there was just one son (thank you!). We asked for ages and found that most of the daughters are in their 40s and early 50s; the average age was 47.5. The youngest daughters was 33

"Thanks to all the members who took the time to respond to our Survey, printed in the last issue. The responses we received were very illuminating."

and the oldest, 61. For the mothers, most are in their 70s with the youngest at 57 and the oldest respondent 83 years of age. Our son was 47.

Most people don't remember how they heard about DES Action, which is understandable since over half of our respondents have been members for more than ten years. For those who do remember, the Internet and the newspaper were the leading sources.

One can see how the concerns of the DES-exposed population

have shifted over by analyzing what issues motivated people to join DES Action and which issues are of greatest concern to members today. While most joined simply to keep informed and up to date, specific health issues that topped the list included infertility and cancer. Today, the issue that is of greatest concern is potential health effects on the third generation exposed, followed closely by worries about the effect of DES exposure on menopause. Other "high-scoring" concerns include the link between DES and breast cancer, auto-immune diseases, and long-term effects in general.

We asked members to tell us which services they appreciate the most, and overwhelming numbers (84%) cited this newsletter. The other services most frequently mentioned are, in descending order: other publications; research advocacy,

Your top priority areas of research:

**66% said:
DES Third
Generation
Effects**

**63% said:
Menopause
and Aging**

**54 % said:
Autoimmune
Issues**

Other frequently cited issues included:

Cancer risks for DES sons & DES daughters
Reproductive health risks for DES sons
The need to educate urologists and ob/gyns about DES
Causes of infertility for DES daughters

legislative updates, physician referral, the DES Third Generation Network; and our website. Services we can improve upon included developing a more comprehensive health care provider referral list for both daughters and sons; expanding the newsletter; and educating doctors and nurses. Plans for these activities are under discussion.

When DES Action started 25 years ago, there were more active affiliate groups in various states and regions. Much of this had to do with the fact that at that time, most DES daughters were coping with infertility and a myriad of other new health problems and felt the need for a support group that met frequently. While our health issues have not gone away, the need for this kind of group has ebbed for most people. Many have found some measure of support through the online DES daughter's listserve.

In order to assess the interest and potential for expanding DES Action affiliates, we asked three questions. We learned that just less than half of respondents knew another DES-exposed individual in their own community. When asked "would you be interested in initiating a state or community affiliate group?" Five people said yes and 53 replied no. However, two-thirds, or 41 people, would be interested in

joining an existing DES Action group. The Board of Directors will be discussing these mixed results as we focus on the best ways to move forward.

Understandably, most people are not able to travel at their own expense to a national conference, although about 20% of respondents were willing and able to do so, and they shared many ideas for conference topics and speakers. At the top of the list were researchers and doctors who would share updates and speak about medical care for DES-exposed people. Other suggestions included reports on third generation research, menopause, HRT, and alternative menopausal treatments, and auto-immune diseases. Hearing from members of Congress who have supported us and learning about legal experts were other ideas cited by respondents.

We included a section on the CDC's DES Update because this campaign will reach many thousands of people and because we are eager to hear your ideas. Your many useful suggestions included ideas for media outreach; educating health care providers; more teleconferences; have an annual "Ask Your Mom" media campaign; and other specific ideas. Some respondents offered to help distribute DES Update materials—we will be contacting those who offered to help.

Finally, many offered additional comments of enthusiastic support and appreciation for our work. Each of these expressions of support are treasured, because they make this work so meaningful to those of us who do it every day. Thank you, one and all, for your comments and your ideas. We will be looking closely at each and every one as we discuss strategies to make DES Action an even stronger organization that can make greater strides for the DES-exposed community. ■

What services can we improve upon and how?

These were the suggestions most often given:

- Have bigger newsletter
- Conferences: new speakers, topics, forums
- More information on the website
- Speak at doctors' conferences
- Provide more information on holistic/alternative medicines
- Develop a more comprehensive physician referral list
- More physician referrals for DES sons
- More research on third generation
- TV ads and greater media coverage of DES issues

America's Other Drug Problem

by Nora Cody

SINCE drug companies are now allowed to advertise directly to consumers, we've seen their splashy ads on television, magazines and newspapers. We are joined in our concern by many medical experts. Two respected former editors of the *New England Journal of Medicine*, Drs. Marcia Angell and Arnold Relman, wrote about this in the December 16, 2002 issue of the *New Republic*. Their article, "How the Drug Industry Distorts Medicines and Politics: America's Other Drug Problem" gives recommendations:

- Stopping direct to consumer ads
- More access to generic drugs by changes in patent law
- Letting big buyers like Medicare negotiate prices on prescription drugs
- Ending drug company influence on clinical trials

A few weeks before this article appeared, a London market

consultant company Datamonitor reported that the top 14 drug companies had spent over \$9 billion in 2001 in promoting drugs in the United States and five European countries. They noted that this contrasts with \$4.6 billion in 1998.

Consumers foot the bill for this—helping the pharmaceutical industry spend more on marketing than on what they want us to believe is their emphasis on research and development. The coalition DES Action belongs to, Prevention First, is more needed than ever. The goals are:

- To counter the advertising of prescription drugs, especially when the ads are false and misleading.
- To inform the public about the side effects and limited benefits of breast cancer "prevention" pills such as tamoxifen and raloxifene.

- To highlight the problems associated with treating a risk factor as though it were a disease.
- To promote a view of public health that stresses primary prevention—identifying and eliminating disease-causing agents in our food, water and air.
- To promote greater awareness of the Precautionary Principle in health.

In response to the advocacy of Prevention First, the FDA has reprimanded AstraZeneca, the makers of tamoxifen, three times for ads found to overstate the benefits and understate the risks of this anti-cancer drug heavily promoted for healthy women.

We shudder to think of how many DES-exposed there would be if Eli Lilly and the other drug companies had advertised DES with pictures of smiling mothers and happy babies. ■

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too important to delay. Researchers from the major federal study of July 2002 (discussed in our Summer 2002 issue) known as the Women's Health Initiative now write that HRT does not improve the quality of life. This was assumed by some doctors and their patients to be a good reason for menopausal and post-menopausal women to take these drugs, even after considering risks for heart disease and cancer.

In this study of 16,608 women aged 50-79 years, with an intact uterus, half of them were given a combined estrogen-progestin drug (Prempro) and half of them a placebo. The scientists report "no significant effects on general health, vitality, mental health, depressive symptoms, or sexual satisfaction." The authors conclude "For most women these small benefits do not outweigh the risks of heart

attack, stroke, blood clots, and breast cancer associated with combined hormone therapy."

Christopher Li et al, "Trends in Incidence Rates of Invasive Lobular and Ductal Breast Carcinoma," *JAMA*, March 19, 2003

Jennifer Hays et al, "Effects of Estrogen plus Progestin on Health-Related Quality of Life," *New England Journal of Medicine*, May 8, 2003. ■

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Better epidemiological tracking of chronic diseases and developmental disabilities is needed. More detailed and widespread monitoring of human exposure to toxicants is vital, including health tracking of conditions, biomonitoring to inform individuals and healthcare professionals of actual body burdens of known and suspected toxicants. Good, uncompromised science must be the underpinning of all such efforts.

Where the weight of plausible scientific evidence shows that contaminants are likely to contribute to increased disease, exposures should be reduced or eliminated. The Precautionary Principle should become a guiding factor in public health and environmental policy.

Efforts in environmental health have too often been fragmented. Our emerging realization of the scale of the problem, and the growing body of scientific information linking plausible cause with effect, encourages a commensurate response.

A new emphasis on a diverse and inclusive collaboration is essential to successfully reduce public exposure to environmental toxicants and to implement preventive strategies.

Established researchers and health-affected groups can collaborate in conducting important new research. Medical organizations can work with health-affected groups towards better approaches to treatment, services, or interventions. Organizations that are engaged in the issues of environmental justice, poverty, civil rights and human rights must be represented and work together as equal partners.

Everyone concerned—health-affected groups, scientists, health professionals, and environmental organizations—can serve as resources for each other to reduce public exposure to environmental toxicants and contribute significantly toward creating a healthier society.

The Collaborative on Health and the Environment has been established to address this need. Please visit our website at www.cheforhealth.org

DES ACTION TRIBUTE PROGRAM

We'd like to offer a great idea for that person who has everything: the DES Action Tribute Program. Our Tribute Program is a way for you to make your contribution in someone's honor or memory. Holiday gifts, birthdays, anniversaries, or memorial remembrances—all are appropriate occasions for a Tribute gift.

When you send your Tribute gift to DES Action, simply enclose a note indicating in whose honor and for what occasion the gift is given. Make sure to include the honoree's name and address as well as your own. We send an acknowledgment letter to you and to the honoree. The amount of the gift is not mentioned.

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for 78% of mental illness, anxiety 15%, 6% depression and anxiety together, and 6% psychosis.

Finally, because of the possibility of prenatal hormone influence on brain behavior, this study shows that DES sons have a greater frequency of left handedness than do the controls. This influence is not found in DES daughters. The authors conclude:

"In summary, our data suggest that prenatal exposure to DES, a potent synthetic estrogen, does not materially influence sexual behavior in adult offspring. In particular, we saw no increase in the likelihood of homosexual contact, a possibility that has been widely hypothesized. We noted a relation between DES exposure and left-handedness in men, a finding

that may be consistent with an influence of DES on cortical asymmetry and laterality. Although we found no association between DES exposure and mental illness in women, the question is not easily addressed in these data because survey respondents may under-represent those affected by mental illness and may misclassify outcomes in these self-reported data."

From Report to Action

THIS January, the Food and Drug Administration (FDA) told all drug companies making products that include estrogen, or the combined estrogen/progestin pill of HRT, that they must include a boxed warning or label. This new boxed alert, the highest level of warning permitted by the FDA, requires companies to state in the box that these estrogens may increase risks for heart attack, strokes, blood clots and breast cancer. The labeling includes the suggestion that these products, whether patches, creams or pills, should be used only on a "lowest dose, shortest duration" basis.

Such a "black box" statement means that every woman who is prescribed these drugs will have

"Many women are not aware of the possible effects on their health from taking hormone replacement."

a clear statement of risks. Not everyone saw the media stories in July 2002, proving risks of HRT, so that many women are not aware of the possible effects on their health from taking hormone replacement. This FDA action gives them that information. The

New York Times in its January 9, 2003 story, wrote that

"But with 10 million women in this country still taking estrogen products, the agency's decision sends a strong message, medical experts said. Putting a black box on a drug's label is a regulatory action and it is not taken lightly.

'Having a black box on the label is a big deal,' said Dr. Susan Hendrix, a gynecologist at Wayne State University in Detroit who was an investigator in the federal study. 'It's pretty astounding to go from a year ago thinking this is one of the most benign drugs to a 180-degree turn in the opposite direction.'"

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