

# News from DES Studies

THE DES Follow-up Study run by the National Cancer Institute (NCI) recently published their newsletter reporting on the status of their studies. This newsletter is sent to the women and men currently participating in the studies. The last questionnaire was sent in 1997. The next questionnaire will be sent this summer. Since this is the largest follow-up study of DES-exposed, we thought that readers would be interested in the following excerpts from the report.

"The NCI DES Follow-Up Study is a nationwide research study that includes more than 15,000 women and men. The purpose of the study is to examine the long-term health effects of exposure to diethylstilbestrol (DES)...Information is collected for this study using questionnaires.

"To determine how DES affects health, we compare two groups of people: those who were exposed to DES and those who were unexposed."

## DES Studies in Progress

### Autoimmune Diseases

"Very few studies have been done on the possible relationship between DES exposure and the

development of autoimmune diseases. Interest in studying whether DES is related to autoimmune disease was prompted by studies in mice. These studies showed that DES negatively affected the immune system...

"An early report from the DESAD study found that DES-exposed daughters were somewhat more likely to report autoimmune diseases than were unexposed women. We are following up on this early report by studying these diseases in greater detail. If you reported an autoimmune disease, such as lupus, rheumatoid arthritis, optic neuritis, or idiopathic thrombocytopenic purpura on the 1994 or 1997 questionnaire, we may contact you to ask permission to obtain the details of your diagnosis."

### Third Generation Study

"Some studies of laboratory animals suggest that the effects of DES can be multigenerational... In response to concerns about possible multigenerational effects in humans, the NCI has started a study of third-generation women. The primary goal of the study is to find out whether the known effects of DES, particularly gynecologic conditions, are present in the 'DES granddaughters.'

"The Third Generation Study, which started in August 2000, is enrolling adult daughters of women who participated in the

DES daughter's study...we expect to enroll about 700-800 young women."

### Infertility

"...We assessed infertility using different definitions. We found...that exposed daughters were about 1.5 times as likely to have never been pregnant as unexposed daughters. Exposed daughters were 2.2 times as likely as unexposed daughters to have tried for 12 or more months to become pregnant without success. This was found both for women who had never been pregnant (primary infertility) and those who had already been pregnant (secondary infertility). It appeared that most of the increase in infertility was due to problems with the fallopian tubes or uterus. Consistent with this, about twice as many exposed as unexposed daughters reported surgical treatment for infertility. Exposed daughters had only a slight increase in infertility due to problems with hormone levels or ovulation compared with unexposed daughters and, when only primary infertility was considered, there was no difference. In addition, equal proportions of exposed and unexposed daughters reported ever taking medications that bring on ovulation."

### Cervical Dysplasia in DES Daughters

"Your answers to the 1994 questionnaire were used to

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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/](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](mailto:des-sons-request@egroups.com). Direct questions to [des-sons-owner@egroups.com](mailto:des-sons-owner@egroups.com).

The DES-Family list welcomes all DES-exposed, their family, and friends. To join, e-mail [listserv@sact.com](mailto: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](mailto: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.

#### DES Action USA National Office

610-16th Street #301  
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#### DES Sons Network

104 Sleepy Hollow Place  
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#### DES Third Generation Network

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#### DES Action San Jose (California)

5835 Terrazo Court  
San Jose, CA 95123

#### DES Action Massachusetts

P.O. Box 126  
Stoughton, MA 02072

#### DES Action Minnesota

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Coon Rapids, MN 55448

#### DES Action Pennsylvania

Box 398  
Nescopeck, PA 18635

#### DES Action Washington

719 15th Avenue, East  
Seattle, WA 98112

### 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  
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England  
France  
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The Netherlands  
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# Soy Formula and Cancer

"Uterine adenocarcinoma in mice treated neonatally with genistein," Retha Newbold et al, *Cancer Research* June 1, 2001.

**DISCOVERIES** of the effects of the synthetic estrogen DES on humans exposed in utero has opened the door to a wide range of scientific inquiry. Researchers have studied birds and fish with malformations and sterility after exposure to chemical pollutants like dioxin, compounds called xenoestrogens, i.e., having estrogen effects. A new area of inquiry centers on such "endocrine disruptors." This study field is that of phytoestrogen, or plants that have estrogen. John McLachlan, former science director of the National Institute of Environmental Health Sciences (NIEHS) and now director of the Tulane Center for Bioenvironmental Research, has called estrogens the "earth mother" of all hormones, pointing out that plant life 400 million years ago produced phytoestrogens.

Now his colleagues at the NIEHS, led by Retha Newbold, report that female mice treated neonatally with injections of genistein, the estrogen compound in soy, later develop the same uterine adenocarcinoma as do mice treated with DES. In fact, the incidence is higher: at 18 months, 35% of the genistein treated mice had uterine adenocarcinoma compared with 31% of the DES exposed mice. The genistein mice had the same reproductive tract abnormalities that have been found in DES mice: cystic ovaries, malformed oviducts, and an increase in multi-oocyte follicles (more than

one egg in a follicle) that have been shown to be less fertile.

Theo Colborn and her colleagues, whose book *Our Stolen Future* brought attention to environmental estrogens and disruption, maintains a web site ([ourstolenfuture.org](http://ourstolenfuture.org)) to continue presenting research. Their review of the Newbold study emphasizes:

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**"Female mice treated neonatally with injections of genistein, the estrogen compound in soy, later develop the same uterine adenocarcinoma as do mice treated with DES. In fact, the incidence is higher: at 18 months, 35% of the genistein treated mice had uterine adenocarcinoma compared with 31% of the DES exposed mice."**

"This study makes two profoundly important points:

- It raises very large issues about the wisdom of basing infant formula on soy. Decades of research with DES showed time and again that effects first found in experiments with mice were then confirmed in studies of people.
- It confirms once again that estrogens at the wrong time in development can have extremely adverse effects, no matter whether they are from natural sources like

soy or synthetic sources like DES. What matters is whether they penetrate the chemical defense systems of the developing organism at a vulnerable moment in development, one at which the developing organism would normally be using natural estrogen signals to guide development. At these moments, inappropriate estrogens can alter development by changing the intensity of the estrogen signal."

Newbold stated in the abstract that:

"The developing fetus is uniquely sensitive to perturbation with estrogenic chemicals. The carcinogenic effect of prenatal exposure to diethylstilbestrol (DES) is the classic example. Because phytoestrogen use in nutritional and pharmaceutical applications for infants and children is increasing, we investigated the carcinogenic potential of genistein, a naturally occurring plant estrogen in soy, in an experimental animal model previously reported to result in a high incidence of uterine adenocarcinoma after neonatal DES exposure...At 18 months, the incidence of uterine adenocarcinoma was 35% for genistein and 31% for DES. These data suggest that genistein is carcinogenic if exposure occurs during critical periods of differentiation. Thus, the use of soy-based infant formulas in the absence of medical necessity and the marketing of soy products designed to appeal to children should be closely examined."

# Double Exposure

CHRIS COSGROVE is an American DES daughter and tall girl. She wonders—if Hox genes play such a crucial role during embryonic development, might not there be other genes that control development during puberty? And if tall girls were receiving a carcinogenic drug like DES during that period of development, could that account for similar negative consequences?

Chris wrote her story for the May 2000 issue of the Australian *Tall Girls Newsletter*.

"As an American 'tall girl' who never knew anyone else who had been treated with hormones for being 'too tall', it was my great good fortune to discover recently that there are others like me in Australia. I believe there are probably more of us in the U.S. as well, but so far it has been hard for us to find one another. I hope that will change.

"I did not realize what I had been given until I was well into my thirties. It was then, after a miscarriage and the premature stillbirth of twin daughters, that I learned I was a DES daughter. Then, while reading up on the DES that was given to my mother and many other women in a misguided attempt to prevent miscarriage, I stumbled upon the word Stilbestrol, a brand name for DES. I suddenly felt ill. Stilbestrol was the name of the drug I had been given as a teenager for five years to prevent me from growing too tall. So not only had I been exposed in utero to the effects of DES, but I had received large doses of this drug as a teenager.

"Growing up in a small town in southern California, my mother and father were worried when I rapidly grew four inches in the eighth grade. My periods had not started yet, and my mother, who was concerned,



Chris Cosgrove

took me to the family doctor. He referred me to an internist, Dr. Peter Maurice, who x-rayed my ankles, my wrists, my pituitary gland, and perhaps other body parts I have forgotten about. The physical exam itself was embarrassing. The doctor acknowledged that he could find nothing wrong with me, but yes, he told my parents, he believed I could grow quite tall. (No surprise there. Both parents were tall). His suggestion? A pill, not much different than a birth control pill, as he described it to

my mother and me. This was 1964 and I suspect the marvels of the birth control pill were just being realized. What we didn't realize, was that Stilbestrol was something quite different.

"When I first started taking the drug, it upset my stomach terribly. I threw up several times a day and headed off to school with a bottle of green liquid medicine that was supposed to keep the nausea at bay. It didn't. My mother took me back to the doctor. He asked me to swallow another pill in the office, which I did, and promptly threw it up two minutes later.

"Somehow he managed to get the vomiting under control, but I had another problem. My breasts would leak. In gym classes, doing exercises on our stomachs, I would get up and have a wet shirt. Or I could be walking down the street and suddenly I would have what I later recognized to be a 'let down' reflex of a nursing mother. When I complained about this to the doctor he told me it was caused by 'too much petting in the back seat of a car,' that I was somehow stimulating my breasts to leak.

"At 15, I was too embarrassed to report this to my parents. But since petting in the back seat of a car or anywhere else was an activity I had yet to experience, I knew he was wrong.

"During my first year in college Dr. Maurice determined that I was now diabetic. His tests showed that I couldn't metabolize sugar well, so I was put on

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oral medication for diabetes. In my second year of college when I came down with mononucleosis and was hospitalized, the medical staff was completely confused about the strange drugs I was taking. They told me I was not diabetic and that the drug he'd given me for that was harmful. I was to throw it away. They contacted Dr. Maurice about the Stilbestrol and after recovering from mono, my mother decided maybe it was time to stop all the drugs.

"Hallelujah! But coming off the Stilbestrol was not so easy, either. I couldn't sleep and when I did I had terrible nightmares. I bled so voluminously that I needed a D & C.

"I ended up measuring just under 6 feet tall. My mother is a bit shorter, my father a bit taller, my brother is 6 feet 5 inches. I always thought it was ironic that the models who graced all the magazines when I was a teenager—Verushka, Jean Shrimpton—were all tall, too—yet for them it was an advantage, while for me it was treated as a disease.

"I was fortunate to be able to have one daughter; many DES daughters are unable to have any children. But I have had endless gynecological problems and no way of knowing which DES exposure caused what. Bit by bit, parts of my reproductive tract have become diseased and

been removed. I've suffered from depression on and off for years, and have always wondered how much of that was due to the five years of Stilbestrol.

"I used to wonder why nobody was investigating people like me. I thought then, that perhaps I was the only one, and what would be the point of finding out how five years of DES given to a teen might affect the rest of her life? Now I know there are a number of us who were stupidly experimented upon by, in my case, someone who really had no idea what he was doing. If there is any comfort to be had in any of this, it is knowing that I am not completely alone." ■

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address the question of whether DES exposure might increase the risk of cervical dysplasia. We compared the number of biopsy-confirmed dysplasia that occurred from 1982 through 1985 in 3,899 DES-exposed daughters to that in 1,374 unexposed daughters and found that DES-exposed daughters were twice as likely to have cervical dysplasia as women who were not exposed. Women who were first exposed to DES earlier in gestation tended to have higher risks than those exposed later.

"It is possible that the increased risk of dysplasia in this study may simply be due to the fact that DES-exposed women tend to have more Pap smears

and other tests to diagnose cervical tissue changes which might otherwise not be diagnosed. It is reassuring that we found no increased risk of invasive cervical cancer. However, because cervical dysplasia is easily treatable, we believe that it is important for DES-exposed women to continue to receive a regular, yearly Pap smear with thorough examination of the upper part of the vagina and the cervical transformation zone."

**DES Sons**

"While DES daughters have been studied extensively, there have been few studies of the DES-exposed males . . . (our) study found no significant

increase in the overall cancer rate in the exposed group when compared both to the unexposed controls in the study and the general male population. When each cancer site was examined individually, there was a slight excess of testicular cancer. However, when these numbers were compared to national rates and rates in unexposed men, the excess rate was not significant and could be explained on the basis of chance alone. Nonetheless, exposed males should perform monthly self-examination for lumps in their testicles as recommended for all young men. We will continue to follow the exposed cohort as it ages in order to identify all health and cancer risks." ■

# DES Mom in Congress

WHEN you need help, it's good to have a friend. Those exposed to DES have friends in Congress. Louise Slaughter, (D-NY), has actively worked for years on legislation to provide funding for research and education on DES issues. Another representative, who works on our behalf, is Representative Patsy Mink (D, Hawaii). She feels very strongly about DES issues, because she is a DES Mom.

This 13th term Congresswoman first learned of her DES exposure when she opened a letter from the University of Chicago. "It told me I'd been part of a medical experiment, without my knowledge, and it had tragic results. I'd been prescribed DES while pregnant."

Mink says she was "a basket-case" when she found out. It was an emotional time for her and her family. Subsequently she became part of the Dieckmann study which tracked DES mothers and their offspring.

"It turned me completely against pharmaceutical companies. Now I take every opportunity to testify against them. In Congress I do what I can to support legislation appropriating funding for research and education on DES issues. It's so very important."

Mink credits DES Action for keeping the whole sordid matter from being quietly swept under the carpet by well-heeled drug companies. But she'd like to see increased public involvement too. "We need more help championing the cause. It sounds trite, but keeping your

representatives on Capitol Hill aware of your concerns is the best way to get things done."



*Patsy Mink*

"The important thing is to remain organized and stay connected," says Mink. In her experience, what is heard from constituents plays an enormous role in shaping legislation.

When pressed on how best to do it, she suggests possibly designating a particular month as your DES Month. Then, mark your calendar and every year during that month, each victim contacts her, or his Congressional representative. "Keep reminding Congress how important funding is for DES research and awareness campaigns. Your personal stories can have an impact. That's the best way."

## Tort Reform Battle

Looming on the horizon is a Congressional battle over Tort Reform. "It's a huge issue for the DES exposed, as well as for all people who have been victimized in this country," says Mink. "It's definitely a high priority."

When George W. Bush was running for President, he promised to push for Tort Reform on the national level. Simply put, it would limit the amount of damages courts can award victims. Drug companies are big supporters of Tort Reform.

"This would be disastrous for anyone who has been victimized," warns Mink.

She has fought similar proposals in the past and will continue to do so because she thinks it's wrong to limit the liability of drug companies and other businesses which do harm.

But Mink concedes that taking a case to court is far from easy. She filed suit against the University of Chicago and pharmaceutical companies. After presenting her case, the defendants settled. But in other situations, women have undergone grueling cross examinations from drug company lawyers who want to blame them for problems clearly caused by exposure to DES.

"Filing suit isn't for everyone," says Mink, "but victims should be allowed to sue if they so choose. Juries should not be denied the right to give large damage awards where warranted. Defendants should pay for their actions."

Mink recognizes that beating back Tort Reform won't be easy. She reiterates how urgent it is for the DES exposed to establish contact with their Congressional Representatives. "It's all the more important when a big bill like Tort Reform is being debated. We are

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# Notes from Nora

## Grandchildren Covered Under DES Liability

THE above headline appeared on February 22 in the *New York Law Journal*, reporting on a small victory for the DES exposed community. The U.S. Court of Appeals for the Second Circuit ruled that insurance companies must pay damages won by third generation claimants in DES cases. Insurers for the pharmaceutical company and DES-maker E.R. Squibb & Sons had attempted to avoid covering third generation cases by arguing that since third generation claimants "did not exist during the relevant policy period—even in utero—and having no body, could suffer no bodily injury..."

Using the argument that only injuries (referred to as "injuries-in-fact") that actually took place

during the relevant period of coverage should be paid for, the insurance companies tried to have the court bar coverage for

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**"They argued that DES is eliminated from the body of the mother and fetus within days, and that the drug only has an effect in utero, and therefore the later development of cancers in the second generation could not be considered injuries-in-fact under the policy."**

second generation cases as well. They argued that DES is eliminated from the body of the mother and fetus within days,

and that the drug only has an effect in utero, and therefore the later development of cancers in the second generation could not be considered injuries-in-fact under the policy. But the court affirmed that "injury-in-fact can also include, in appropriate circumstances, the inevitable predisposition to illness or disability as a result of cell mutation caused by DES. This is not a case or a risk or predisposition that is heightened or discounted by other contingencies, choices, or influences."

Given that third generation DES lawsuits have been banned in New York State (see *Voice* #41, Spring 1991), any steps towards recognition of the real damages to the third generation are positive developments. ■

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talking about losing our rights for justice. Don't leave it up to someone else if it really matters to you."

(EDITOR'S NOTE: Obtaining Congressional contact information is easy on the Internet. For your Senator's name and address, go to: [www.senate.gov](http://www.senate.gov) For your Representative's name and address, visit [www.house.gov](http://www.house.gov) and scroll down to "Write your Representative." Those who are not online can call their local library to get the name and address for their Representative and their Senators.) ■

## Letters to the Editor

Dear Editor:

Thank you for showing an excerpt from *DES Stories* in your Spring 2001 newsletter. A correction for the zip code in the mailing address is listed below. The book is a photographic tribute to millions of people around the world exposed to DES. Every DES-exposed person has an important story to tell. Thank you for spreading the word about DES and helping us tell our stories. For info about *DES Stories* please contact our web site or mail address:

Margaret Lee Braun  
Author, *DES Stories, Faces and Voices of People Exposed to Diethylstilbestrol*  
Visual Studies Press, Box 10114, Rochester NY 14610  
Web: [www.DESstories.com](http://www.DESstories.com)



## Sanford Freedman, 1922-2001

Sanford Freedman, a DES father and neuropsychologist who played a pivotal role in establishing the state of Massachusetts' DES awareness program, died from non-Hodgkin's lymphoma on May 29 in Newton, MA.

Dr. Freedman's first daughter Amy was among the group of eight young women with clear cell adenocarcinoma reported on by Arthur Herbst in the famous article that led to the discontinuation of the use of DES during pregnancy. Amy was just 17 years old when she died from vaginal cancer in 1968. The Freedman's lost their second daughter Sharai in January, 1981.

In February, 1981, Dr. Freedman's wife Marian read about the efforts by DES exposed people to persuade the Massachusetts legislature to establish a DES education program in the state. Marian contacted Andrea Goldstein, our Massachusetts coordinator, and asked if they could help. Andrea asked Dr. Freedman to speak to the legislators about what DES had done to his family. When he began speaking, the room fell silent and a legislative aide turned to Marian and said "that'll do it." It did—funding for the DES program passed and Andrea Goldstein credits Dr. Freedman's eloquent testimony. The Massachusetts program in the state public health department is the longest-running state DES education program and one of the few programs in existence today.

The DES community owes a debt to Sanford Freedman and his family. He will be greatly missed.

23 YEARS OF

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