

DES Daughters More Prone to Uterine Fibroids

"Prenatal diethylstilbestrol (DES) exposure is associated with uterine leiomyoma development," by Donna Day Baird and Retha Newbold, Reproductive Toxicology 20 (2005).

**Reviewed by Pat Cody
& Fran Howell**

This new study confirms that what is already known to happen in DES exposed laboratory mice also holds true for humans. DES Daughters are at higher risk for developing uterine fibroids.

Leiomyoma is the medical name for fibroids. They are benign tumors that sometimes cause "pain, bleeding, infertility and pregnancy complications. They are the leading indication for hysterectomy," say the study's authors.

The researchers, Baird and Newbold, work at the National Institute of Environmental Health Sciences. They had previously found a link between DES exposure and uterine fibroids in mice.

To see if this association is found in women, they studied 858 women between the ages of 35-49 who were randomly selected from a District of Columbia health center. Because black women have a significantly higher risk of fibroids, the analysis separated the two ethnic groups (413 black, 365 white).

What they found was a higher proportion of women exposed to DES before birth developed fibroids. Large fibroids tended to be more common in those reporting DES exposure no

matter what the woman's race.

Twenty six percent of DES exposed white women developed tumors, compared with 15% of unexposed white women. Among black women in the group, 60% of the DES exposed developed fibroids, while 32% of the unexposed black women did.

The researchers conclude that, "our findings suggest uterine fibroids

should be added to the list of long-term health problems" that DES

Uterine fibroids should be added to the list of long-term health problems DES Daughters may experience.

Daughters may experience. What the study could not assess was whether DES Daughters develop fibroids earlier than unexposed

women. The scientists say their findings suggest that is a possibility — because fibroids in DES Daughters tended to be larger than in unexposed

continued on page 3

Infertility Drug, Clomid, Boosts Uterine Cancer Risk

"Uterine cancer after use of clomiphene citrate to induce ovulation," M. Althuis et al, *American Journal of Epidemiology*, April 1, 2005.

Reviewed by Pat Cody

Although no data was taken as to DES exposure among this group, we're reporting on this study because many DES daughters have taken Clomid (also known as Serophene) as part of infertility treatments.

These researchers, led by a scientist from the National Cancer Institute, begin their article by pointing out that clomiphene cit-

rate (Clomid) increases estradiol levels and thus may increase the risk for cancer of the uterus.

They surveyed health data from 8,431 women in the United States who were evaluated for infertility during the 23 years from 1965 to 1988. Through 1999, 39 uterine cancers were reported from this

Many DES daughters have taken Clomid (also known as Serophene) as part of infertility treatments.

group. The risk increased with the total Clomid dose and was highest among women who had never been pregnant, and were obese. They also found that risk was greatest for

those who first used Clomid 20 or more years ago. The authors com-

continued on page 3

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Join The DES Action Daughters or Sons Listserv

Want to be in touch, via email, with other DES exposed individuals? As a benefit of being a DES Action member you can join either the DES Action Daughters, or DES Action Sons, listserv.

That way you can ask questions and share experiences common only to those of us who are DES exposed.

To join the DES Action Daughters listserv simply send a blank email to:

DESActionDaughters-subscribe@yahoogroups.com

To join the DES Action Sons listserv simply send a blank email to:

DESActionSons-subscribe@yahoodgroups.com

You'll receive an email back from Yahoo! Groups confirming your request to join. It offers two registration options and the easiest is Option 2. Click "Reply" so the note is sent back.

Once we've checked to be sure you are a current DES Action member, you'll receive a welcome to the listserv letter explaining how to send messages. Then you can participate in the email conversations, or just quietly read and enjoy the learning experience.



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1- (800) DES-9288 (800) 337-9288

desaction@columbus.rr.com

www.desaction.org

Executive Director

Fran Howell

Program Director

Kari Christianson

VOICE Editor

& Research Liaison

Pat Cody

Board of Directors

President: Patti Negri

Vice President: Michael Freilick

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Treasurer: Stephanie Kanarek

Karen Fernandes

Ann Giblin

Kim Mazeres

Candy Tedeschi

VOICE Design and Layout

Solunar Graphics, Columbus

(614) 488-9962

Printing

CPMM Services Group, Columbus

(614) 447-0165

Contributors

Elizabeth Levine Wandelmaier

Kari Christianson

Pat Cody

Fran Howell

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DES Action Contacts

United States

**DES Action
USA National Office**
158 South Stanwood Road
Columbus, OH 43209
desaction@columbus.rr.com
www.desaction.org
800-337-9288

DES Action Sons Network
104 Sleepy Hollow Place
Cherry Hill, NJ 08003
msfreilick@hotmail.com

**DES Action
Generations Network**
Box 21
Mahwah, NJ 07430
desactiongen@optonline.com

DES Action Massachusetts
14 Canterbury Dr.
Canton, MA 02021

DES Action Pennsylvania
Box 398
Nescopeck, PA 18635
www.desactionpa.org

DES Action Los Angeles

6324 Ivarene Ave.
Hollywood, CA 90068
Pinkkaire@aol.com

DES Action International

Australia
DES Action Australia, Inc.
PO Box 282
Camberwell 3124 Vic. Australia
desact@vicnet.net.au
www.desaction.org.au

DES Action Australia - NSW
14 Edmundson Close
Thornleigh NSW
2120 Australia
C_devine@bigpond.net.au

Canada
107-5890 Monkland Avenue
Suite 15
Montreal, QC H4A 1G2
(514) 482-3204
1-800-482-1-DES
www.web.net/~desact
desact@web.net

England

DES Action UK
Box 128, Blaydon LDO, NE40 3YQ
England
101274.15@compuserve.com

France

Reseau DES France
12 rue Martinon
40000 Mont de Marsan
France
reseaudesfrance@wanadoo.fr

Ireland

Carmichael House
North Brunswick St.
Dublin 7 Ireland
www.desactio.ie
info@desaction.ie

The Netherlands

DES Centrum
Wilhilminapark 25
3581 NE Utrecht
The Netherlands
des@descentrum.nl

Uterine Fibroids *continued from page 1*
women they studied, meaning the tumors in the DES exposed may have started earlier, or grown faster, or both.

Of note is that uterine fibroids are tumors of smooth muscle origin and according to the scientists they develop as clonal growths. The researchers point out that while DES studies have mainly focused on epithelial lesions in the past, this work shows that, "smooth muscle cells are also DES targets."

The incidence of uterine fibroids

increases up until women enter premenopausal age. With the youngest DES exposed women in the United States now in their 30s, many are at the age for developing them. In Europe, and in other parts of the world where DES was prescribed for several years longer, the youngest DES Daughters are still in their late 20s. The good news for many women is that uterine fibroids regress after menopause.

Though DES is no longer prescribed during pregnancy, the legacy left by the tragedy may move science

forward. Many chemicals in the environment possess estrogenic, or endocrine-disrupting features similar to the synthetic hormone, DES. So the researchers wonder whether those chemicals "may contribute to increased incidence of reproductive problems and various diseases," in the general population. "Although it remains to be shown whether exposure to these chemicals at environmental levels is harmful, the findings support the need for research on a broad range of health outcomes, including uterine fibroids."

Clomid *continued from page 1*
ment is that:

"The significant latency effect suggests that clomiphene may be an initiator of carcinogenesis and is consistent with the fact that uterine carcinomas are generally slow-growing tumors. Long latency may explain in part why studies that included fewer than 10 years of follow-up failed to find an association between clomiphene use and uterine cancer, underscoring the importance of long-term follow-up of infertility cohorts."

The report concludes:

"In summary, our study is the first known to suggest that clomiphene increases uterine cancer risk and to demonstrate evidence of both a dose-response and latency effect. Clomiphene did not increase either ovarian or breast cancer risk in this cohort; however, we observed slight elevations in risk for both cancers among women followed for more than 20 years....

"Clomiphene was approved for clinical use in the United States in 1967 and is now one of the most widely used drugs in the management of infertility. By 2025, between 5.4 and 7.7 million U.S. women are projected to seek treatment for infertility annually. It is therefore of mounting public health importance to clarify the relation between clomiphene use and

uterine cancer. Fortunately, uterine cancer is often diagnosed at early stages because of symptoms (see box) and has good survival rates."

DES Daughters who were prescribed Clomid are urged to have that fact noted on their patient history

form so their health care providers are alert for this cancer.

Those who are dealing with infertility should give careful consideration to the risks of using Clomid before starting it.

The decision should be made after consultation with your doctor.

The risk increased with total Clomid dose and was highest among women who had never been pregnant.

Early Warning Signs and Symptoms of Uterine Cancer

According to **MayoClinic.com**, "endometrial (uterine) cancer often develops over a period of years. Your first clue that something is wrong may be vaginal bleeding that's uncommon for you."

MayoClinic.com goes on to say, "most cases of endometrial cancer develop in postmenopausal women, whose periods have stopped. However, a small percentage of cases affect women younger than 40. Signs and symptoms may include:

- Prolonged periods or bleeding between periods
- More frequent vaginal bleeding or spotting during the years leading up to menopause (perimenopause)
- Any bleeding after the time of menopause
- A pink, watery or white discharge from your vagina
- Pelvic pain, especially late in the disease
- Pain during intercourse
- Weight loss

Third Generation DES Exposed Get a New Name — DES Grandchildren

By Fran Howell

What's in a name? Confusion, if those who use it don't agree on what it means! That's especially true in the DES community and especially among scientists who must be extremely precise.

So, at a recent National Cancer Institute meeting about DES issues, researchers and DES exposed representatives all agreed on what to call Third Generation DES exposed individuals.

To keep them consistent with the family nomenclature of DES Mothers, DES Daughters and DES Sons, the grandchildren of DES Mothers will be called just that — DES Grandchildren, or more specifically, DES Granddaughters and DES Grandsons.

DES Action Program Director Kari Christianson, who was at the table when the decision was made, is pleased with this clarification. "It shows that scientists are interested in studying this particular group of DES exposed individuals or they wouldn't spend time making sure we are all speaking the same language," she says.

Recognized DES attorney Sybil Shainwald thinks this change may help in litigation.

"Calling someone Third Generation exposed implies that the injuries were genetically caused by DES exposure. But there are many cases of premature births resulting from such reproductive tract anomalies as an incompetent cervix. These babies often suffer severe injuries. Using the term DES Grandchild untangles the injury from direct connection to DES exposure passed down through the generations. This terminology should result in a better understanding by courts, which have been reluctant to award damages in so-called Third Generation cases. It is extremely important that consumer advocates, lawyers,

"It shows that scientists are interested in studying this particular group of DES exposed individuals or they wouldn't spend time making sure we are all speaking the same language."

doctors, and researchers use the same terminology!"

"I'm pleased with the change," says DES Action Generations Network Coordinator Elizabeth Levine Wandelmaier. "In fact, our group

used to be the Third Generation Network, but we felt since name changes were underway that we should update, too."

She adds, "since researchers are examining the possibility that DES health problems may extend into the fourth generation, and beyond, we wanted to be ready to represent DES Great Grandchildren, if need be, hence the name Generations Network."

The new email address for the DES Action Generations Network is: desactiongen@optonline.net

Educate Your Doctor With a Clip-out Fact Sheet on the DES Exam

By Fran Howell

If we can't educate all health care providers, we can at least educate the doctors who are seeing us!

Many DES Daughters worry that their health care providers are not doing the recommended DES gynecological exam. So DES Action is providing you with a fact sheet (pages 5 and 6) to clip-out of this issue and bring when you go in for your next appointment.

Cut it out and hand-deliver it. Since the Centers for Disease Control and Prevention (CDC) developed the guidelines, they come from a government agency most doctors and health care providers respect. It is also written in language they understand.

The exam is not all that much different from a routine gynecological exam done on a non-exposed woman, so doctors should not balk. But from a DES exposed Daughter's perspective, it is important to have it done correctly!

As a DES Daughter you need **annual** gynecological cancer

screenings — at a minimum. So the flip side explains that to your doctor so you don't have to.

Do not mail this fact sheet — the receptionist is busy and probably won't track down your file. Bring it to your health care provider when you go in so you know it gets into the right hands.

Before you leave the office, insist your doctor put the sheet in your patient file — to make it readily available for future visits.

Please make a copy and keep it in your files before handing it over, because you never know when you'll need the information again — perhaps if you change doctors?

It would get costly for DES Action to deal with multiple copy requests, what with printing, mailing and staff time expenses. As you know, we operate on a shoe-string budget so your help in keeping our costs down is greatly appreciated!

Our hope is that this fact sheet will be a useful tool as we continue to advocate for our own health, and educate doctors about DES.



Department of Health and Human Services

Centers for Disease Control and Prevention

Annual Exam for DES Daughters

Although health effects of DES exposure differ among DES Daughters, health care providers should monitor these women for abnormal genital tract structures, particularly for clear cell adenocarcinoma (CCA) of the vagina and cervix.

- **Clinical breast exam**
- **Vulvar inspection**
- **Vaginal and cervical inspection**
 - Inspection of epithelial surfaces of vagina
 - Rotation of speculum to view anterior & posterior walls of vagina
- **Cytology**
 - Separate specimens from vagina fornices and cervix — all specimens placed on one slide or in liquid media
- **Palpation of vagina and cervix (an essential part of the exam)**
 - Palpate entire length of vagina, including fornices
 - Note ridges or structural changes
- **Bimanual rectal-vaginal exam**
- **Biopsy**
 - Areas of thickening or induration found during vaginal and cervical palpation
 - Palpable nodules
 - Discrete areas of varied colors or textures
 - Atypical colposcopic findings
- **Colposcopy**
 - If abnormal findings on Pap smear
- **Iodine staining of vagina and cervix**
 - To confirm boundaries of epithelial changes
 - Use Lugol's solution (half strength)
- **Frequency of follow-up visits**
 - Determine on individual basis
 - Focus on changes since initial evaluation — include: palpation, inspection, cervical & vaginal cytology
 - Colposcopy, iodine staining, biopsy as needed
 - Ask about interval bleeding or abnormal vaginal discharge



Recommended Early Cervical and Vaginal Cancer Detection Guidelines for DES Daughters

Lifelong Annual Screening

Beginning at age 30, women who have had 3 normal Pap test results in a row may get screened every 2 to 3 years with either the conventional (regular) or liquid-based Pap test. **Women who have certain risk factors such as diethylstilbestrol (DES) exposure before birth**, HIV infection, or a weakened immune system due to organ transplant, chemotherapy, or chronic steroid use **should continue to be screened annually.**

Women 70 years of age or older who have had 3 or more normal Pap tests in a row and no abnormal Pap test results in the last 10 years may choose to stop having cervical cancer screening. **Women with a history of DES exposure before birth**, cervical cancer, HIV infection or a weakened immune system **should continue to have screening as long as they are in good health.**

http://www.cancer.org/docroot/PED/content PED_2_3X_Pap_Test.asp?sitearea=PED

The American College of Obstetricians and Gynecologists agrees: annual screenings are vital for DES Daughters.

http://www.acog.org/from_home/publications/press_releases/nr07-31-03-1.cfm

Renowned Women's Health Journalist Speaks At DES Action Event

By Elizabeth Levine Wandelmaier

DES Action sponsored a presentation by Barbara Seaman on May 15 at the Huntington Library, as part of *Prevention Is the Cure Week*, on Long Island.



Barbara Seaman

Seaman opened her talk with a history of synthetic estrogen, including the startling information on just how early scientists knew it was carcinogenic. She related her personal conversations with Sir Charles Dodds, the British scientist who in 1938 created DES, the first synthetic estrogen. He was disturbed by the post-war overuse of hormones, including DES.

I highly recommend her book, *The Greatest Experiment Ever Performed on Women: Exploding the Estrogen Myth*. It includes much of the specific information that Seaman presented. (DES Action has copies of the paperback edition available for \$11.50, which includes postage and handling. Just let us know if you'd like one).

Seaman told the group how drug companies use parts of studies, rather

than complete information, in persuading the medical community to use their products. For example, one study concluded that estrogen helped prevent osteoporosis. However, the drug companies neglected to mention that women in this study already had their ovaries removed.

Several DES activists also made up an impromptu panel at the session in Huntington. Sybil Shainwald, a well-known DES attorney, in response to a question from a DES Mother, said that women given DES while pregnant should feel angry, not guilty, about DES.

Candy Tedeschi, a Long Island nurse practitioner and DES Action Board member, explained vaginal and cervical tissue changes in DES Daughters and how those potential changes result in the need for four-quadrant Pap tests for all DES Daughters.

DES Action Program Director Kari Christianson also spoke briefly. She had just attended the NCI DES Follow-up Study Steering Committee meeting in Bethesda, MD.

The presentation, hosted by DES Action, in conjunction with the Huntington Breast Cancer Action Coalition,

was part of *Prevention Is The Cure* week. Each May several groups hold educational events focusing public awareness on environmental links to disease. Rather than work just on cures, the goal is to highlight causes of disease and eradicate them.

It's an encouragement of a "better safe than sorry" attitude toward personal lifestyle, and as HBCAC President Karen Miller says, "the challenge is to change existing political myopia that associates the prevention of disease with a need for more drugs."

An Easy Way to Support DES Action – Fill Out a Survey!

This fall, DES Action is mailing out survey forms to *randomly selected* members. The questionnaire is a follow-up evaluation of the national education effort conducted two years ago by the Centers for Disease Control and Prevention (CDC), called the *DES Update*. The intent is to learn how effective it was.

If you are lucky enough to get a survey in the mail please fill it out right away and send it in.

For each completed questionnaire returned to the CDC, \$25 will be donated to DES Action!!

That's money we can most certainly use!

In the first survey, done prior to starting the CDC's *DES Update*, we had a response rate that was considered excellent. DES Action benefited from member support then, and we hope our members come through for us again this time.

We thank you, in advance for filling out and sending in the questionnaire, if you receive one.

New Web Site *continued from page 8*

mobile society is an on-going and often labor intensive task. This section uses web technology to provide a convenient opportunity for all involved to keep in touch. Potentially, it may result in an administrative cost savings for this research effort.

The "FAQ" section answers the most frequently asked DES questions posed to the Center Coordinators during the 2001 follow-up study.

The final sentence in the "Background" section is very important for everyone interested in the continuation of DES research: "Therefore, the DES Follow-up Study, which has followed the largest cohort of documented DES exposed people over time, represents the only remaining opportunity to study DES health ef-

fects on a population followed over a period of time." (And, yes, there's even a photo on the web site of the intrepid Steering Committee, gamely reconvening after an unexpected shower from the automatic sprinkler system still visible behind the group!).

As the above quote so perfectly and repetitively states, without the NCI DES Follow-up Study there would be no research in the United States that is able to seek the long-term health effects of DES exposure in humans. This impressive web site gives us a window into that on-going research, which is funded by a special bill that DES Action members and staff worked tirelessly to get passed in Congress. I urge you to take a moment to see the web site.

www.DESfollowupstudy.org

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Important New Web Site Provides DES Research Information



By Kari Christianson

www.DESfollowupstudy.org is the new internet address for the NCI DES Follow-up Study. Since 1992, the National Cancer Institute (NCI), in collaboration with research centers throughout the United States, has been conducting an ongoing study of more than 21,000 DES exposed Mothers, Daughters, and Sons. In 2000 the study was expanded to include a questionnaire for DES Granddaughters.

Every few years participants are asked questions about their recent health, which is analyzed to determine the rates of cancers, benign breast and gynecologic tumors, precancerous conditions of the cervix, autoimmune diseases (like rheumatoid arthritis),

psychiatric disorders, and genito-urinary conditions (such as epididymal cysts among DES Sons).

Easy access is provided to research papers that were developed by studying results gathered from the questionnaires. Just click on the Publications section to read reports from the DES Follow-up Study. (Much of it will look familiar to DES Action members as we keep you updated on research results in the *Voice*).

To learn more about this on-going research, go to the "Background" section. It offers everything from a timeline and history of DES research at NCI, to a description of each of the cohorts (groups), which are part of this important research study. It's a fascinating view into work that has

been quietly underway for decades.

The web site was originally conceived as an update and thank you vehicle just for study participants. But the NCI DES Steering Committee, with the strong encouragement of its consumer advocate members, understood the importance of sharing this valuable information with the entire DES exposed community. So the site was developed for public access in order for everyone to be able to visit it and learn more about DES research.

But there is a working side to the site, too. The "Contact" section was created to give study participants an easy way to update their address information. Since the questionnaires are mailed out about every five years, updating contact information in our

continued on page 7