

It's HERE! DES Action's Health History Questionnaire

Share Your Health Experiences NOW!

**By Kari Christianson
and Fran Howell**

Over the years, DES Action USA has received thousands of inquiries from DES Mothers, Daughters, Sons and Grandchildren, asking if a particular health problem might be related to DES exposure. In many cases our answer has been, "No one knows."

DES Action is taking steps to help identify whether certain health conditions – beyond those already known – appear more frequently among DES-exposed women and men than among unexposed people, just as we did with our first Health History questionnaire in 1984. Once again, Deborah Wingard, Ph.D., an epidemiologist and Professor in the Department of Family & Preventive Medicine at the University of California San Diego is leading this effort with us.

The 2012 Health History questionnaire is informal. It is not intended to be a scientific study. Rather, your responses will provide a crucial "look" at what's been happening with our health over the past 25+ years. If any trends are suggested by the answers received, we will share this information with researchers who can follow-up with further study.

Because of decades of research by the National Cancer Institute DES Follow-up Study, we do know that many conditions are related to DES (see VOICE 130), and we know that many conditions are not related to DES exposure. With so many millions of people exposed, we expect to hear about the usual range of physi-

cal and psychological problems that are found in the general population. At the same time these "anecdotal" reports do concern us, particularly when they begin to sound repetitive.

A large number of possible conditions are listed on the questionnaire, to help you remember your own health

experience. We encourage you to add other health issues you have experienced. Remember, most of the conditions listed have not been associated with DES exposure, and we are not suggesting that they are related. However, many investigators studying DES

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Cancer Risk Remains a Concern for DES Daughters As They Age

"Higher incidence of clear cell adenocarcinoma of the cervix and vagina among women born between 1947 and 1971 in the United States," *Cancer Causes Control* (2012) 23:207-211, Emily K. Smith, Mary C. White, et al., published online: October 21, 2011 and available at: <http://www.springerlink.com/content/2u260l70x11n26mw/>

Reviewed by Fran Howell

New statistics from a population-based assessment tell an unsettling story none of us wanted to hear. While it is well documented that young DES Daughters are at increased risk for clear cell adenocarcinoma (CCA) of the vagina and cervix, this new analysis also suggests an elevated risk for DES Daughters as they age.

The assessment was done by researchers with the Centers for Disease Control and Prevention (CDC) Division of Cancer and Prevention Control who used data

from two federal cancer surveillance programs: the National Program of Cancer Registries (NPCR) from CDC and the Surveillance, Epidemiology and End Results (SEER) Program from the National Cancer Institute.

Clear cell adenocarcinoma diagnosis rates for women born between 1947 – 1971 were compared with reported CCA diagnosis rates for women born before and after that peak DES-use period.

By identifying CCA statistics for individuals born in years when DES was rarely prescribed, the scientists extrapolated expected numbers of CCA cases for those born during years when DES was the standard of care for problem pregnancies. What they found was disconcerting.

"More cases of CCA than expected were diagnosed among women aged 40-54 who were born when DES was frequently prescribed," says Mary C. White,

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Yes!—I want to join DES Action to stay informed and support a cause I believe in.

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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| <input type="checkbox"/> Friend: \$75 | <input type="checkbox"/> Patron: \$250 | |

Please make checks payable to **DES Action.**

I am a: DES Daughter DES Son Other DES Granddaughter or Grandson
 DES Mother of a: Daughter Son

NAME _____

ADDRESS _____

CITY | STATE | ZIP _____ PHONE _____

E-MAIL ADDRESS _____

Online Support Group for DES Daughters

Want to be in touch, via e-mail, with other DES Daughters? As a benefit of being a DES Action member, you can join the DES Action Daughters Online Support Group. That way you can ask questions and share experiences common only to those of us who are DES exposed.

To join the DES Action Online Support Group simply send a blank e-mail to:

DESActionDaughters-subscribe@yahoo.com

You'll receive an e-mail 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 group letter explaining how to send messages. Then you can participate in the e-mail conversations, or just quietly read and enjoy the learning experience.

Follow DES Action USA on:
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MISSION STATEMENT

The mission of DES Action USA is to identify, educate, support and advocate for DES-exposed individuals as well as educate health care professionals.

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DES Health History Questionnaire

DES ACTION USA wishes to compile information on the health experiences of women and men exposed to DES. Many conditions will NOT be related to DES exposure. However, collecting clues in this way can help us alert the scientific community to possible areas of needed research. We hope that you will help us with this project by filling out the following questionnaire. Also, please pass a copy of this questionnaire, or the survey link on DES Action's webpage, to any DES-exposed person you know.

While we prefer that individuals complete their own questionnaire, there may be situations where a relative may need to complete the survey (i.e. a parent for a young child). If you complete the survey for someone else, please make sure that person is not completing the survey as well. If you need extra room, please use the comment section or additional sheets.

Alternatively, you may complete this questionnaire on Survey Monkey. Please see link on our website: <http://www.desaction.org>

Thank you!

Are you completing this questionnaire about yourself a relative Other: _____
 (If a relative, please make sure your relative is not completing survey as well.)

Is the person a DES-exposed:

| | Know for sure | Think so |
|--------------------|--------------------------|--------------------------|
| Mother..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Daughter..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Son..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Granddaughter..... | <input type="checkbox"/> | <input type="checkbox"/> |
| Grandson..... | <input type="checkbox"/> | <input type="checkbox"/> |

Have you/they ever tried to obtain medical records to verify DES exposure? no yes
 Were the records received..... no yes

Date of birth _____ Height _____ inches
 Current Age _____ years Weight _____ pounds
 Currently live in: USA Canada Europe Australia Other: _____

REMEMBER, MANY OF THESE CONDITIONS WILL NOT BE RELATED TO DES EXPOSURE.

Please indicate if ever diagnosed with any of the following conditions.
 Please also state at what age each was first diagnosed.

| EVERYONE | | Approximate Age First Diagnosed |
|------------------------------|--|---|
| Allergies..... | <input type="checkbox"/> no <input type="checkbox"/> yes | <input type="checkbox"/> <input type="checkbox"/> |
| _____ Mild | | |
| _____ moderate | | |
| _____ severe | | |
| Asthma..... | <input type="checkbox"/> no <input type="checkbox"/> yes | <input type="checkbox"/> <input type="checkbox"/> |
| Dental – gum disease..... | <input type="checkbox"/> no <input type="checkbox"/> yes | <input type="checkbox"/> <input type="checkbox"/> |
| Dental – other problems..... | <input type="checkbox"/> no <input type="checkbox"/> yes | <input type="checkbox"/> <input type="checkbox"/> |
| Depression..... | <input type="checkbox"/> no <input type="checkbox"/> yes | <input type="checkbox"/> <input type="checkbox"/> |
| Diabetes..... | <input type="checkbox"/> no <input type="checkbox"/> yes | <input type="checkbox"/> <input type="checkbox"/> |
| Fractures..... | <input type="checkbox"/> no <input type="checkbox"/> yes | <input type="checkbox"/> <input type="checkbox"/> |
| How many? _____ | | |
| Heart disease..... | <input type="checkbox"/> no <input type="checkbox"/> yes | <input type="checkbox"/> <input type="checkbox"/> |

EVERYONE

Approximate Age First Diagnosed

| | | | | |
|---|-----------------------------|------------------------------|--------------------------|--------------------------|
| Herpes | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Shingles..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Kidney or bladder problems..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Lupus..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Multiple sclerosis..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Rheumatoid arthritis..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Thyroid disease (hypo, hyper, Graves disease) | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Other autoimmune condition | | | | |
| _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |

Other conditions (not in following lists):

| | | | | |
|-------|-----------------------------|------------------------------|--------------------------|--------------------------|
| _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |

MOTHERS ONLY

| | | | | |
|-----------------------------|-----------------------------|------------------------------|--------------------------|--------------------------|
| Cystic (lumpy) breasts..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Breast cancer..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Cancer of the uterus..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Other cancer: _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |

SONS / GRANDSONS ONLY

| | | | | |
|---|-----------------------------|------------------------------|--------------------------|--------------------------|
| Birth defect: _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Hip dysplasia..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Hypospadias..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Undescended testicle..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Epididymal cysts (benign tumors on testicles) | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Infection or inflammation of testes..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Low sperm count..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Poor sperm quality..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Infertility / fertility problems..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Enlarged prostate..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Prostate cancer..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Other prostate problems _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Testicular cancer..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Other cancer: _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |

DAUGHTERS / GRANDDAUGHTERS ONLY

| | | | | |
|---------------------|-----------------------------|------------------------------|--------------------------|--------------------------|
| Birth defect: _____ | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |
| Hip dysplasia..... | <input type="checkbox"/> no | <input type="checkbox"/> yes | <input type="checkbox"/> | <input type="checkbox"/> |

Approximate Age First Diagnosed

- Adenosis (may cause vaginal mucus/discharge) no yes
- Cervical anomalies (collar, ridge, hood)..... no yes
- T-shaped uterus..... no yes
- Endometriosis..... no yes
- Ovarian cysts..... no yes
- Paraovarian cysts..... no yes
- Polycystic ovarian syndrome (PCOS)..... no yes
- Pelvic inflammatory disease (PID)..... no yes
- Uterine fibroids..... no yes
- Irregular periods..... no yes

Until what age: _____ years

- Painful periods (dysmenorrhea)..... no yes
- Poor cervical mucus..... no yes
- Luteal phase defect..... no yes
- Fallopian tube problems..... no yes
- Do not ovulate (prior to menopause)..... no yes
- High levels of prolactin..... no yes
- Pituitary tumors (these are non-malignant)..... no yes
- Ectopic pregnancy..... no yes
- Miscarriage..... no yes
- Preeclampsia..... no yes
- Hysterectomy..... no yes

Age: _____ years

- Menopause..... no yes

Age: _____ years

- Cystic (lumpy) breasts..... no yes
- Dysplasia (CIN)..... no yes

Cancer in situ: where?

_____ no yes

Clear cell cancer: vagina..... no yes

Clear cell cancer: cervix..... no yes

Other cancer of vagina or cervix:

_____ no yes

Cancer of the uterus..... no yes

Breast cancer..... no yes

Other cancer:

_____ no yes

_____ no yes

DES DAUGHTERS / GRANDDAUGHTERS ONLY

Have you ever been pregnant?..... no yes IF YES, please complete the following:

- # pregnancies.....
- # live births.....
- # live births < 37 weeks (premature).....
- # live births < 6 pounds.....

Have you ever been diagnosed with infertility or problems getting pregnant? no yes

Did you ever use any of the following fertility treatments?

| | <input type="checkbox"/> no | <input type="checkbox"/> yes | Length of time | # live births |
|-----------------------------------|-----------------------------|------------------------------|----------------------------|----------------------|
| In vitro fertilization (IVF)..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> years | <input type="text"/> |
| Fertility drugs without IVF..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> years | <input type="text"/> |
| Artificial insemination (AI)..... | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> years | <input type="text"/> |
| Other treatment: _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="text"/> years | <input type="text"/> |

DAUGHTERS or SONS

If your mother is no longer living, please state cause and age of death:

EVERYONE

Has a physician ever said your illness/health condition was/is unusual (e.g. at your age or number of times)? _____

IF YES, please describe:

Race/ethnicity - please check all that apply: (optional)

- Asian / Asian-American Black / African-American
- Hispanic Non-Hispanic White Other: _____

Sexual orientation: (optional)

- Gay/Lesbian Heterosexual Bisexual Self-Identify: _____

Other comments (please use additional sheets if necessary):

REMEMBER, MANY OF THESE CONDITIONS WILL NOT BE RELATED TO DES EXPOSURE.

THANK YOU FOR HELPING US WITH THIS QUESTIONNAIRE!

Please return by June 15th:

Deborah Wingard, Ph.D.
DES Action Research Consultant
Dept. of Family & Preventive Medicine, 0607
University of California, San Diego
La Jolla, CA 92093-0607

Health History Questionnaire from page 1

emphasize the need to monitor carefully the health experiences of those of us who are exposed to DES—prenatally, generationally or directly.

Please fill out the four-page questionnaire as completely as possible if you are a DES Mother, DES Daughter, DES Son, DES Granddaughter, DES Grandson or any subsequent DES Generation.

This Health History question-

naire is also available online at: <http://www.desaction.org/index.html>. Whether filled in on paper or online, your responses are anonymous, private and secure. **The deadline for completing the questionnaire is June 15, 2012.**

A report on the findings of the Health History questionnaire will be published in the VOICE in a future issue, once Dr. Wingard has gathered your survey answers. Researchers tell DES Action that the time after receiv-

ing questionnaire responses is like “panning for gold,” because it takes careful evaluation and comparison with national health records to determine if there is any association or a higher incidence of a health problem in the DES-exposed population.

This is an exciting opportunity for all of our DES voices to be heard. Your responses will help all of us learn more about how and if DES exposure is involved in our health experiences.

CCA Rate Spike from page 1

Sc.D., who heads the CDC’s Epidemiology and Applied Research Branch. “Although we measured an increased risk, CCA is a very rare cancer even among women with known in utero exposure to DES. These analyses were possible because of the availability of high quality data from multiple population-based cancer registries over several years.”

The analysis also picked up an increased incidence of CCA among young women in their late teens and early twenties, which is consistent with the already known increased CCA risk for DES Daughters in that age group.

“If the marked elevated risk of CCA among this birth cohort was due primarily to in utero DES exposure, our findings suggest that the large number of women exposed in utero to DES in the United States may still be at special risk for CCA as they grow older,” says White. “This analysis could be repeated in the future to examine CCA risk as women age.”

National Cancer Institute DES Follow-up Study researchers previously reported DES Daughters were 40 times more likely than women in the general population to develop CCA.

The respected American Congress of Obstetricians and Gynecologists advises more frequent Pap/pelvic exams for DES Daughters than for unexposed women. And the National Cancer Institute tells DES Daughters they need a “four-quadrant” Pap in which cell samples are taken from all sides of the upper vagina, as well as from the cervix. Of note is that because of the increased vaginal cancer risk for DES Daughters, an annual

Pap is prudent to check the vagina even if the cervix is removed in a hysterectomy.

For directions to give your doctor on how a proper DES Daughter Pap/pelvic exam should be done go to: <http://www.desaction.org/desdaughters.htm>.

White suggests a question about prenatal DES exposure be included on medical intake forms. “Doctors should have this relevant informa-

tion when recommending Pap exams based on a woman’s risks.”

As is often the case, those of us in the DES community stay better informed on DES issues than most doctors. Therefore, DES Daughters may want to share this new study when telling doctors they want a Pap/pelvic exam every year. There is clearly no known upper age limit for the increased CCA cervical/vaginal cancer risk for DES Daughters.

New Cervical Cancer Screening Guidelines Do Not Apply To DES Daughters

Annual Pap Tests Still Recommended

Recently released guidelines by the U.S. Preventive Services Task Force (USPSTF) call for less frequent Pap screenings for most women. The recommendations allow for skipping several years at a time for women with previously normal Pap results.

But for DES Daughters the critical portion of these guidelines is the disclaimer:

“This recommendation statement does not apply to women who have received a diagnosis of a high-grade precancerous cervical lesion or cervical cancer, women with in utero exposure to diethylstilbestrol, or women who are immunocompromised (such as those who are HIV positive).”

DES Daughters may have to advocate for the health care they need by pointing this out to doctors. Remind your provider that you should

have cervical cancer screenings every year because of your increased risk for clear cell adenocarcinoma (CCA) of the vagina and/or cervix. This cancer is rare even for DES Daughters, but with a lifelong increased risk you should have an annual Pap exam.

If the doctor has any questions you can provide a link to the *Annals of Internal Medicine* web page: <http://bit.ly/GEkzdL> where the USPSTF guidelines are posted. The DES exclusion is the second sentence in the Recommendations Section.

After a hysterectomy DES Daughters still need to be screened every year to check for CCA of the vagina.

For a copy of the specific DES Daughter Pap/pelvic exam directions to give your doctor go to the DES Action USA website: <http://www.desaction.org> and click the DES Daughter link.



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Health History Survey Inside

HUGE VICTORY IN DES BREAST CANCER CASE

A federal magistrate in Boston ruled against 14 drug companies, including Eli Lilly, Merck and Bristol-Meyers Squibb, when she ordered them to negotiate damage settlements with 53 DES Daughters who claim their breast cancers are linked to prenatal DES exposure.

The drug makers responded with a motion asking U.S. Magistrate Judge Marianne Bowler to reconsider. But she held firm and denied their request.

During months of pretrial hearings, drug company lawyers tried to discredit scientific results from the

National Cancer Institute DES Follow-up Study and expert witnesses put forth by the plaintiffs. However, the judge felt both the science and expert witnesses were compelling enough for the DES Daughters to proceed with their cases.

Facing the possibility of a trial and potentially huge jury verdicts, the drug makers agreed to hammer out settlements rather than continue in court. This is not a class action lawsuit, but rather a bundling together of DES breast cancer litigation.

Representing the DES Daughters is Washington D.C. Attorney Aaron

Levine, along with co-counsel Julie Oliver-Zhang. They say time is a factor. Since the start of this case, five of the DES Daughter plaintiffs have died, with four more battling stage IV breast cancer. "The drug companies can delay, stall and be difficult but the judge's ruling demonstrates that she intends to stay in control and keep negotiations on track between the parties," says Oliver-Zhang.

New DES breast cancer cases are being accepted by Aaron Levine's firm, as well as by other lawyers on the DES Action attorney list:

www.desaction.org

