Risky pregnancy drug raised daughters' cancer odds

A drug that millions of pregnant women took decades ago to prevent miscarriage and complications has put their daughters at higher risk for breast cancer and other health problems that are showing up now, a new federal study finds.

Many of these daughters, now over 40, may not even know of their risk if their mothers never realized or told them they had used the drug, a synthetic estrogen called DES.

The new study suggests that infertility is twice as common and that breast cancer risk is nearly doubled in these daughters.

Debbie Wingard is one of them. The 59-year-old San Diego woman adopted two boys after being unable to conceive and has had breast cancer twice — when she was 39 and 49.

"There's no knowing what's going to happen as we age. There's always the fear there's going to be another cancer or another outcome," she said. "I don't think I'll ever get to the point where I feel it's behind me."

The sons of DES users also face health risks — testicular problems and cysts — but these are less well studied and don't seem to be as common. Even less is known about the third generation — "DES grandchildren." Some research suggests these girls start menstruating late and have irregular periods, possible signs of fertility issues down the road.

In the United States alone, more than 2 million women and 2 million men are thought to have been exposed to DES while in the womb and may now want to talk with their doctors about when they should be screened for health problems.

"We don't want to cause a panic of everyone rushing out thinking they're going to get cervical or breast cancer. They just need to have that conversation with their physician," said Dr. Sharmila Makihya, women's health chief at the University of Louisville.

The average woman has about a 1 in 50 chance of developing breast cancer by age 55;
DES, or diethylstilbestrol, was widely used in the United States, Europe and elsewhere from the 1940s through the 1960s to prevent miscarriage, premature birth, bleeding and other problems. Many companies made and sold it as pills, creams and other forms.

Studies later showed it didn't work. The government told doctors to stop using it in pregnancy in 1971, after DES daughters in their late teens and 20s were found to be at higher risk of a rare form of vaginal cancer. Further research has tied DES to infertility and various pregnancy problems.

"They've been identified one at a time. Nobody's been able to get the whole picture," said Dr. Robert Hoover, a researcher at the National Cancer Institute. The new study, which he led, "takes the woman and looks at everything that can happen as a result of this drug," and adds evidence for some previously suspected risks like breast cancer, he said.

Results are in Thursday's New England Journal of Medicine.

The study started in 1992 and involved about 4,600 DES daughters and a comparison group of 1,900 similar women whose mothers had not used DES. Their health was tracked over time through surveys and medical records. Their average age at the last followup was 48.

In the study, researchers found these rates of health problems in DES daughters compared to non-exposed women:

—Breast cancer, 3.9 percent versus 2.2 percent.
—Cervical pre-cancer, 6.9 percent versus 3.4 percent.
—Infertility, 33.3 percent versus 15.5 percent.
—Early menopause, 5.1 percent versus 1.7 percent

These complications were seen among women who were able to become pregnant:

—Preterm delivery, 53.3 percent versus 17.8 percent.
—Miscarriage, 50.3 percent versus 38.6 percent.
—Tubal pregnancy, 14.6 percent versus 2.9 percent.
—Stillbirth, 8.9 percent versus 2.6 percent.
—Preeclampsia (high blood pressure during pregnancy), 26.4 percent versus 13.7 percent.

The claim of added breast cancer risk is being tested by 53 women in a lawsuit against DES makers under way now in Boston. One of them is Jackie White, 48, who lives in Centerburg, Ohio, north of Columbus. She said she had a misshaped uterus and reproductive problems, and found a lump last year that turned out to be breast cancer. Tests showed 20 tumors in one breast, two pre-cancers in the other and spread to her lymph nodes.

"I ate a low-fat diet. I exercise faithfully so I was not overweight. I had none of the normal risk factors," she said.

When and how often to screen women for breast cancer is the subject of much debate. A government task force recommends that women at average risk of breast cancer get mammograms every other year starting at age 50, and talk to their doctors about screening before then. Many medical groups urge starting at age 40.

DES exposure needs to be considered with the whole picture of a woman's risk, said Dr. G. Wright Bates, director of reproductive medicine at the University of Alabama at Birmingham.
"In some cases, frequent Pap smears and early mammography or breast MRI may be warranted for women with DES exposure," he said.

Others are focused on possible risks to the next generation.

Sally Keely, who was part of the federal study, and her husband are both offspring of women who took DES during pregnancy. Keely, 49, of Kalama, Wash., had miscarriages and a tubal pregnancy and required fertility treatments to have a daughter, now 9.

"I would like to push for more funding on the third generation exposed so I would know best how to advise my daughter," she said.

Fran Howell, executive director of DES Action USA, an advocacy group based in Jupiter, Fla., adopted a daughter, now 20, after being unable to conceive.

"So many of the DES daughters worry about problems with their children," she said.

"The DES ends with me."

Online:

Cancer Institute: http://www.cancer.gov/cancertopics/factsheet/Risk/DES.

CDC: http://www.cdc.gov/des/consumers/about/concerns—daughters.html

Advocacy group: www.desaction.org

Marilynn Marchione can be followed at http://twitter.com/MMarchioneAP

Copyright 2011 The Associated Press. All rights reserved. This material may not be published, broadcast, rewritten or redistributed.

For more information about reprints & permissions, visit our FAQ's. To report corrections and clarifications, contact Standards Editor Brent Jones. For publication consideration in the newspaper, send comments to letters@usatoday.com. Include name, phone number, city and state for verification. To view our corrections, go to corrections.usatoday.com.

More from USATODAY

Black Dog Syndrome bad luck for rescue shelters

'Hockey mom' arrested on suspicion of having sex with son's team members

Omega-3 supplements don't help, may hurt some ICU patients

Nancy Grace: Amanda Knox verdict was 'miscarriage of justice'

Brett Favre says his comments on Aaron Rodgers were misinterpreted

More from the web

12 Ways to Protect Your Joints

5 Things You Should Never Wear Over 50

DinnerTool's Picks: Warm Up with Top Soup Recipes

How to bake acorn squash

Have Healthy Eating Habits All Day

What Do You Think?

To leave a comment, you need to sign up.
"This drug does horrible things to their daughters and, as a side note it has bad effects on the sons, but we don't care enough to look in to that any deeper".

I'll be sure to remember that next time someone asks me to support a woman's cause.

Sadly, this is not news. It's been known for some time. Women of my generation were the first generation of victims, and effects are now showing up in their daughters...and sons! I suspect they will show up in the next generations too.

What is criminal is that the drug was marketed to doctors as a miscarriage preventative "after" the drug companies knew it was not effective, and those doctors kept prescribing it.

Like the damage that Thalidomide did in the 50s, drug companies will take profit from drugs they know are dangerous.

How do we know if we took this or not?! Scary.

This not new...my dr told me about in in mid 1980's since my mom had taken DES. It bothers me that this article suggest that a mammogram would be "warranted for women with DES exposure' in light of recent scrutiny that medical procedure. Either way...educate the children so they can watch their health.

Like the damage that Thalidomide did in the 50s, drug companies will take profit from drugs they know are dangerous.

The drug company did NOT know that Thalomid had these side effects because reproductive toxicology was not done back then. It is because of this drug that reproductive
toxicology studies were developed. Thalomid effects rapidly dividing cells (like a fetus) which is why it is now used to treat various types of cancer. You should get your facts straight before criticizing. That said, I have noticed that many people who complain about "corrupt pharma" are also the first ones to complain when the FDA holds up a promising new drug because they want to see more evidence of safety. You can't have it both ways, folks!

1 reply

dna
8:34 PM on October 5, 2011
This is not news. The problems with DES have been known since at least the 1970's

1 reply

Suzanne Perot
5:27 PM on October 6, 2011
An article that tells women that they can get breast cancer from DES is news, lady. Or man. The problems with DES didn't stop in the 1970's. Daughters of DES have a plethora of health problems due to that drug that are documented. Now we have to worry about breast cancer. For me it was a reality.

1 reply

techresmgt
8:33 AM on October 6, 2011
Here we go again; one would think men's health concerns did not exist. In this female centric crazy society they are doing their best to engineer, it almost seems plausible. Almost. News flash; there are generally two gender classification on the planet. Two.

1 reply

rhythmnation2008
12:16 PM on October 6, 2011
I am truly sorry that the younger generation of women are suffering, but at least their mothers took care of their pregnancies the best way they knew how. I also agree with the other commentors that said this is not "new news". This information was available about 20-30 years ago.