

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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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-

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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

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.