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Serving the DES-exposed community since 1978

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SCIENCE CONFIRMS WHAT MILLIONS OF DES DAUGHTERS KNOW FROM EXPERIENCE

Women exposed before birth to the anti-miscarriage drug diethylstilbestrol (DES), which was prescribed to their mothers primarily from 1938 thru 1971, know all too well of the health problems it inflicted on them as individuals. But an article in the October 6, 2011, *New England Journal of Medicine*, “Adverse Health Outcomes in Women Exposed in Utero to Diethylstilbestrol,” provides a comprehensive look at what is known to date of medical problems for DES Daughters as a whole.

“Here it is, what we’ve experienced for the past four decades. It isn’t as if we didn’t have confirming information previously, because we did, but it was not collected all in one article in a respected publication,” says DES Action USA Program Director Kari Christianson. “Look at what this drug has done. What other prescription drug has had this much negative impact over the lives and health of women?”

According to lead author Robert N. Hoover, M.D., of the National Cancer Institute, researchers can now say conclusively that prenatal DES exposure is linked to a host of health problems for DES Daughters, including infertility, ectopic pregnancy, loss of second-trimester pregnancy, preterm delivery, stillbirth, a rare vaginal/cervical cancer and breast cancer in DES Daughters over age forty, among other health issues.

Many DES Daughters, like Robin Hertzberg, have a hard time building their families because of DES-caused infertility and, in her case - difficult pregnancies. She considers herself lucky because she was able to have two healthy daughters.

But it wasn’t easy for her. “I was on bed-rest for most of the time with partial placenta praevia and preeclampsia. My first daughter was born six weeks early at less than four pounds. It was terrifying seeing her hooked up to every imaginable tube,” says Hertzberg.

Ginny Bank, like many DES Daughters, endured infertility treatments in an effort to start her family. “After a year I grew tired of my body, and my happiness, being under the control of a doctor. It was a relief to be finished, because even if I’d gotten pregnant, it might have ended badly. Thanks to DES, the risk of preterm labor is high. Once I grieved over the loss of a biological child, I felt liberated and swung into gear. We adopted Mattias when he was three-months old and haven’t looked back,” says Bank.

Meanwhile, at age thirty-nine, DES Daughter Deborah Wingard discovered a lump in her breast not long after having a clear mammogram. Ten years later another diagnosis of cancer meant a second mastectomy. Wingard urges all DES Daughters to pay serious attention to their increased breast cancer risk after age forty.

There is a fear that the DES story is still unfolding. While the NEJM article outlines what is known so far, there remains a nagging concern that additional health problems will emerge as DES Daughters mature past menopause. And those who were able to have children worry what the future holds for the so-called DES Grandchildren.

“While I remain vigilant in watching out for my own health,” says Claire Powers, “I also pay attention to ongoing research into potential health problems for the next generation, like my son. He is healthy and active and I want him to stay that way. Studies have indicated DES Grandchild mice exposed to DES have a higher rate of reproductive organ tumors later in life. We don’t know if it also holds true in humans, so I’m watching it,” Powers says. “To be DES-exposed is to worry a lot.”

The National Cancer Institute DES Follow-up Study is looking at health issues for DES Granddaughters. Results point to the possibility of higher infertility rates for this group, although more research is needed. “There is much we still don’t know about DES exposure, not only for DES Daughters, but also for DES Sons and DES Grandchildren. Continuing the research studies is vital to help millions of individuals who need information to protect their health. The DES community is desperate for answers,” says DES Action’s Christianson.

DES Daughters ought to consider their exposure a part of their medical history in the same way as they view a family tendency toward heart disease or diabetes. Christianson says, “They and their health care providers should pay attention to the particular screening guidelines for DES Daughters. That includes a special Pap/pelvic exam every year to check for a rare cancer, as well as vigilance in doing breast screenings annually after age forty.’

DES Action USA is the national nonprofit organization advocating for those exposed to DES. To learn more visit www.desaction.org.

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Editor’s note: DES Action USA has members around the country who are willing to share their compelling DES stories.

Contact Fran Howell at 561-876-1224 or info@desaction.org to be put in touch with DES Daughters who have agreed to talk publicly about their DES experiences.