
DES ACTION VOICE

A Focus on DIETHYLSTILBESTROL Exposure

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Health Histories of the DES-Exposed

In October, 1984, DES Action asked *Voice* subscribers and other DES-exposed people to complete a questionnaire about various health problems they may have experienced. As we stated at that time, many of the conditions listed on the questionnaire did not necessarily relate to DES exposure. With so many people exposed, we expected to see the same range of health conditions as are seen in the non-exposed population. However, we did think it very important to learn whether any health conditions—other than those already known—are affected by DES exposure. Our questionnaire was an attempt to determine whether any unusual patterns need further investigation through formal studies by scientists and medical researchers.

We present here a summary of those questionnaire results that are of particular interest. It is important to keep in mind that our group is not "typical" of DES-exposed women and men as a whole. Individuals who contact DES Action are more likely to have experienced some kind of health problem that may or may not be related to their exposure. Also, those who have had health problems are more likely to complete the questionnaire than are individuals with no problems. Therefore, questions raised by this preliminary survey *must* be pursued within a more representative, or "unbiased" group. DES Action is now working to encourage the needed follow-up studies.

DES Action mailed the health history questionnaire to 2,000 people who subscribe to the organization's newsletter, and 3,000 others who have contacted us for information, doctor-referrals, etc., but have not contributed financially. Approximately 1,700 people returned a completed questionnaire—520 mothers, 1,079 daughters and 94 sons. 80-90% said they were certain about their DES exposure (about 40% of the mothers and daughters and 20% of the sons have received medical record validation). Exposures were reported between 1941 and the late 1970s (in Mexico).

Many conditions already known, or suspected to be associated with DES exposure, were reported in high numbers on the survey. For daughters, these conditions included adenosis (48.5%), T-shaped uterus (21.5%), cervical anomalies such as hoods or ridges (48%), miscarriages (25%), ectopic pregnancies (8%), premature births (16%) and clear cell cancer of the vagina or cervix (1.5%). Some of these conditions are reported more frequently than one would expect, even from a group exposed to DES, because people who have experienced health problems are more likely to have answered the questionnaire. (For example, daughters who have had clear cell cancer are thought to be more likely to become members of DES Action. Therefore, a higher percentage would have answered the questionnaire.) For sons, conditions frequently reported include undescended testicles (18%), epididymal cysts (13%), low sperm count (21%) and poor sperm quality (13%). Eight percent of the mothers reported breast cancer.

Some conditions that are not, at present, known to be related to DES exposure were reported more frequently than expected. For example, the number of reported colds, flu and respiratory conditions during the past year in daughters and sons was twice as high as the number reported for comparable age and sex groups in a national survey of the general population (the 1979 National Health Information Survey—NHIS). These results of our survey point to a need, therefore, for further study of the rate of infectious illness in women and men exposed to DES before birth.

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Health Histories *continued...*

Number of Respiratory Conditions/100 Persons Per Year			
DES Exposed		National Health Information Survey	
DES daughters	255	NHIS women, 17-44 years	124
DES sons	207	NHIS men, 17-44 years	98
DES mothers	130	NHIS women, all ages	117

People answering our questionnaire also reported apparently higher percentages of asthma, arthritis and lupus, compared with the general NHIS population (see

below). The number of lupus cases, however, were so few (8 daughters and 5 mothers), that the result is difficult to interpret.

Percentages of Asthma, Arthritis and Lupus Reported			
DES Exposed		National Health Information Survey	
Asthma			
DES daughters	9.6%	NHIS women, 17-44 years	2.6%
DES sons	14.9%	NHIS men, 17-44 years	2.2%
Arthritis			
DES daughters	7.8%	NHIS women, 17-44 years	5.8%
DES sons	8.5%	NHIS men, 17-44 years	3.7%
Lupus			
DES daughters	0.7%	General population, all ages	0.002%
DES mothers	1.0%	General population, all ages	0.002%

Other conditions that were reported in our questionnaire answers and that seemed to need further evaluation for daughters include pituitary tumors—generally not malignant—(0.6% compared with 0.007% in women 15-44 years in the general population), high prolactin levels (high levels of the hormone, prolactin, as measured through blood testing), and premature menopause (cessation of menstrual periods significantly earlier than expected). For sons, such conditions include prostate problems (14.9% compared with 0.5% in males 17-44 years in the NHIS).

Remember that while many of these conditions seem to occur much more frequently in the DES exposed, we cannot

draw any conclusions from our survey, due to the self-chosen nature of the group of individuals who participated. We are still examining the responses for certain other conditions included in our questionnaire and do not yet know whether rates among our group are higher than expected. As further information becomes available, we will report it to you.

Our thanks to Dr. Deborah Wingard and her students at the University of California, San Diego, the epidemiologists who worked with us in developing this survey and who compiled the questionnaire results. And, of course, our thanks to all of you who provided such valuable information to us by completing our questionnaire.