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……..	☐	☐
Daughter……..	☐	☐
Son……..……	☐	☐
Granddaughter……..……	☐	☐
Grandson……..	☐	☐

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……	☐ no	☐ yes	☐☐
_____ Mild _____ moderate _____ severe			
Asthma……..	☐ no	☐ yes	☐☐
Dental – gum disease……	☐ no	☐ yes	☐☐
Dental – other problems_____	☐ no	☐ yes	☐☐
Depression……	☐ no	☐ yes	☐☐
Diabetes……	☐ no	☐ yes	☐☐
Fractures……	☐ no	☐ yes	☐☐
How many?_____			
Heart disease……	☐ no	☐ yes	☐☐

EVERYONE **Approximate Age First Diagnosed**

Herpes …….…… ☐ no ☐ yes ☐☐
Shingles…… ☐ no ☐ yes ☐☐
Kidney or bladder problems…… ☐ no ☐ yes ☐☐
Lupus…… ☐ no ☐ yes ☐☐
Multiple sclerosis…….. ☐ no ☐ yes ☐☐
Rheumatoid arthritis…… ☐ no ☐ yes ☐☐
Thyroid disease (hypo, hyper, Graves disease) ☐ no ☐ yes ☐☐
Other autoimmune condition
_____ ☐ no ☐ yes ☐☐
_____ ☐ no ☐ yes ☐☐
Other conditions (not in following lists):
_____ ☐ no ☐ yes ☐☐
_____ ☐ no ☐ yes ☐☐

MOTHERS ONLY

Cystic (lumpy) breasts…… ☐ no ☐ yes ☐☐
Breast cancer…… ☐ no ☐ yes ☐☐
Cancer of the uterus…… ☐ no ☐ yes ☐☐
Other cancer: _____ ☐ no ☐ yes ☐☐
_____ ☐ no ☐ yes ☐☐

SONS / GRANDSONS ONLY

Birth defect: _____ ☐ no ☐ yes ☐☐
Hip dysplasia…… ☐ no ☐ yes ☐☐
Hypospadias…… ☐ no ☐ yes ☐☐
Undescended testicle…….. ☐ no ☐ yes ☐☐
Epididymal cysts (benign tumors on testicles) ☐ no ☐ yes ☐☐
Infection or inflammation of testes…… ☐ no ☐ yes ☐☐
Low sperm count…….. ☐ no ☐ yes ☐☐
Poor sperm quality…… ☐ no ☐ yes ☐☐
Infertility / fertility problems…… ☐ no ☐ yes ☐☐
Enlarged prostate…… ☐ no ☐ yes ☐☐
Prostate cancer…… ☐ no ☐ yes ☐☐
Other prostate problems_____ ☐ no ☐ yes ☐☐
Testicular cancer…….. ☐ no ☐ yes ☐☐
Other cancer: _____ ☐ no ☐ yes ☐☐
_____ ☐ no ☐ yes ☐☐

DAUGHTERS / GRANDDAUGHTERS ONLY

Birth defect: _____ ☐ no ☐ yes ☐☐
Hip dysplasia…… ☐ no ☐ yes ☐☐

			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?

			Length of time	# live births
In vitro fertilization (IVF)……	☐ no	☐ yes	☐ years	☐
Fertility drugs without IVF……	☐ no	☐ yes	☐ years	☐
Artificial insemination (AI)……	☐ no	☐ yes	☐ years	☐
Other treatment: _____	☐ no	☐ yes	☐ years	☐

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:

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