

RESEAU D.E.S. France

Press conference, Paris 1st December 2014

Results of the first French epidemiological study of the consequences of DISTILBÈNE[®] (DES) for the three generations concerned

The 3 generation DES study, initiated in 2013 by Réseau D.E.S. France, a non-profit patient organization, was financed by the ANSM (Agence Nationale de Sécurité du Médicament et des produits de santé) : more than 10 000 questionnaires were completed with 500 000 replies analysed.

SYNTHESIS OF THE RESULTS

A – Essential information

- Risk of breast cancer multiplied by two for the 80 000 French “DES daughters” exposed to DES *in utero*
- For the 3rd generation (children of “DES daughters”), an increase of children born with cerebral-motor disabilities, linked to a higher rate of premature births

B – Confirmation of risks already shown in medical reports

1st generation, “DES mothers”:

- a slight increase in the occurrence of breast cancer (+ 29%)

3rd generation, children of “DES daughters”

- increase of oesophageal atresia (obstruction) for girls and boys
- increase of hypospadias (abnormal position of the urinal meatus) and cryptorchidism (at birth, hypotrophy of the testes) for boys

C – Reassuring information

No increased risk was reported of reproductive organ abnormalities for the 3rd generation girls, whether daughters of “DES daughters” or “DES sons”

D – Future research requested

- 2nd generation, for “DES daughters”: to assess if an increased risk of psychological / psychiatric pathology
- 3rd generation : to assess if an increased risk of cardiovascular malformations

Breast cancer: a twofold risk of breast cancer for “DES daughters”

The French study compared 3436 “DES daughters” and a control group of 3256 non-exposed women of the same age group.

The French study shows, for the “DES daughters” an estimated twofold breast cancer risk, whatever the age group (less than 40, 40 to 49, 50 or more)*. On the one hand, the French study shows no increase of this risk with age advancing, in contrast with the conclusions of the American study (Palmer, 2006) which showed a twofold risk from the age of 40, but tripled for the age group of 50 and more.

The twofold risk is similar to that of a woman with a first degree relative (mother, sister or daughter) who has had breast cancer. This increased risk questions a possible adjustment of breast screening and suggests monitoring yearly.

In France DES prescriptions during pregnancy continued until 1977: thus French “DES daughters” may be pregnant until about 2020.

*these results are submitted to a scientific journal for publication