

HHORAGES - Cohort of Children from Women Exposed to Synthetic Hormones During Pregnancy

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Last update : 09/05/2017 | Version : 1 | ID : 73222

General

Identification

Detailed name Cohort of Children from Women Exposed to Synthetic Hormones During Pregnancy

Sign or acronym HHORAGES

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation CNIL: JB/EM/DC042793, no. 1006460

General Aspects

Medical area Gynecology/ obstetrics
Psychology and psychiatry

Health determinants Genetic
Intoxication
Pollution

Keywords diethylstilbestrol, psychiatric disorders, synthetic oestrogen, ethinylestradiol, behavioural and somatic disorders, exposure, pregnancy

Scientific investigator(s) (Contact)

Name of the director Soyer-Gobillard

Surname Marie-Odile

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Organization HHORAGES-France

Collaborations

Funding

Funding status Mixed

| | |
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| Details | HHORAGES-France, Ile de France Region |
| Governance of the database | |
| Sponsor(s) or organisation(s) responsible | HHORAGES-FRANCE |
| Organisation status | Private |
| Additional contact | |
| Main features | |
| Type of database | |
| Type of database | Study databases |
| Study databases (details) | Cohort study |
| Database recruitment is carried out by an intermediary | A selection of health care professionals |
| Database recruitment is carried out as part of an interventional study | No |
| Database objective | |
| Main objective | <p>The aim of this cohort is to establish the causality between taking synthetic sex hormones during pregnancy and the onset of disorders in children from these pregnancies over a relative long term period.</p> <p>Particular attention is paid to mental health disorders including: recurrent depression, anorexia, bulimia, manic depression, and schizophrenia that are related or not related to defects and/or malformations.</p> |
| Inclusion criteria | Volunteers born between 1946 and 1995. |
| Population type | |
| Age | Adolescence (13 to 18 years) Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) |
| Population covered | General population |
| Gender | Male Woman |

| | |
|--|--|
| Geography area | National |
| Detail of the geography area | France |
| Data collection | |
| Dates | |
| Date of first collection (YYYY or MM/YYYY) | 2002 |
| Date of last collection (YYYY or MM/YYYY) | 2007 |
| Size of the database | |
| Size of the database (number of individuals) | [1000-10 000[individuals |
| Details of the number of individuals | 1,182 children; 529 families |
| Data | |
| Database activity | Data collection completed |
| Type of data collected | Clinical data Declarative data |
| Clinical data (detail) | Direct physical measures |
| Declarative data (detail) | Paper self-questionnaire |
| Details of collected declarative data | The mother's hormone treatment before and during pregnancy; medical records, including prescriptions, and the health problems of the children, including diagnoses or any medical treatments or hospitalisations. Psychiatric disorders (eating disorders, behavioural disorders, obsessive-compulsive disorders, depression and bipolar disorders, schizophrenia and suicides (attempts, death)). |
| Presence of a biobank | No |
| Health parameters studied | Health event/morbidity |
| Procedures | |
| Participant monitoring | Yes |

Details on monitoring of participants

By phone, mail or email. 1,280 records to date were sent to the Association (Paris regional secretariat and treasury). Personalised phone monitoring will be implemented each day to help families in distress (psychiatric illnesses are difficult to manage).

Links to administrative sources No

Promotion and access

Promotion

Link to the document <http://www.hhorages.com/biblio.php>

Link to the document <http://tinyurl.com/PUBMED-HHORAGES>

Link to the document <http://tinyurl.com/HAL-HHORAGES>

Access

Terms of data access (charter for data provision, format of data, availability delay)

Other researchers had access to our cohort and a study is being published; a doctoral thesis has also been supported (team led by Professor M.O. Krebs; Sainte Anne Hospital in Paris). Team led by Charles Sultan (Regional University Hospital) at Montpellier and by Professor Philippe Courtet (Regional University Hospital) at Montpellier whom I have worked with more closely. However, only the families may accept or refuse to participate.

We are currently holding the data from these studies in collaboration with the Sultan (Endocrinology) teams and the Courtet (Psychiatry) teams in Montpellier whom I have been working with for many years.

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only