

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
Email	mog66@wanadoo.fr
Organization	HHORAGES-France
Collaborations	
Funding	
Funding status	Mixed

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	<p>Adolescence (13 to 18 years)</p> <p>Adulthood (19 to 24 years)</p> <p>Adulthood (25 to 44 years)</p> <p>Adulthood (45 to 64 years)</p>
Population covered	General population
Gender	<p>Male</p> <p>Woman</p>

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