

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

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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

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).
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Links to administrative sources	No
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Promotion and access

Promotion

Link to the document	http://www.hhorages.com/biblio.php
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Link to the document	http://tinyurl.com/PUBMED-HHORAGES
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Link to the document	http://tinyurl.com/HAL-HHORAGES
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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
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Access to individual data	Access on specific project only
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