

# CONGENITAL HYPOTHYROIDISM - Newborn screening for congenital hypothyroidism - Development of young adults treated for congenital hypothyroidism since neonatal period: health, fertility, pregnancy outcomes and children's health

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HÔPITAL ROBERT DEBRÉ AP-HP

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## General

### Identification

Detailed name Newborn screening for congenital hypothyroidism - Development of young adults treated for congenital hypothyroidism since neonatal period: health, fertility, pregnancy outcomes and children's health

Sign or acronym CONGENITAL HYPOTHYROIDISM

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation Accord CNIL n°906178 (31/07/2006)

### General Aspects

Medical area Endocrinology and metabolism

Health determinants Genetic

Keywords vital status, socio-professional insertion, fertility, children, Health episodes, treatment, quality of life, morbidity, pregnancy, environment

### Scientific investigator(s) (Contact)

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Organization AP-HP

Collaborations

Funding

Funding status Public

Details PHRC 2005, Fondation WYETH

Governance of the database

Sponsor(s) or organisation(s) responsible Hôpital Robert Debré

Organisation status Public

Additional contact

Main features

Type of database

Type of database Study databases

Study databases (details) Longitudinal study (except cohorts)

Database recruitment is carried out by an intermediary A selection of health institutions and services

Database recruitment is carried out as part of an interventional study No

Additional information regarding sample selection. Prospective Inclusion cut-off date: 01/12/1988

Database objective

Main objective General objective: To analyse the development into adulthood for individuals treated for congenital hypothyroidism (CH) since neonatal period, thanks to routine screening established in France since 1978. Secondary objectives: - to assess health at adult age, quality of life and socio-professional insertion and fertility as well as children's health i.e. children of subjects treated for CH. To research thyroid developmental anomaly and general development during first year of life. - to identify

sub-groups of candidate patients according to phenotype for genetic study. The analysis of pregnancy progress and outcome as well as thyroxine requirements during pregnancy is included in the study of women treated for CH. - To improve treatment strategies (children, adolescents, adults, pregnant women).

Inclusion criteria Hypothyroidism detected during neonatal period between 1978 and 1988

## Population type

Age Newborns (birth to 28 days)  
Infant (28 days to 2 years)  
Early childhood (2 to 5 years)  
Childhood (6 to 13 years)  
Adolescence (13 to 18 years)  
Adulthood (19 to 24 years)  
Adulthood (25 to 44 years)  
Adulthood (45 to 64 years)  
Elderly (65 to 79 years)  
Great age (80 years and more)

Population covered Sick population

Gender Woman

Geography area National

Detail of the geography area Multicentric cohort throughout metropolitan France (20 centres):

## Data collection

### Dates

Date of first collection (YYYY or MM/YYYY) 01/1978

### Size of the database

Size of the database (number of individuals) [1000-10 000[ individuals

Details of the number of individuals 1804

### Data

Database activity Data collection completed

Type of data collected Declarative data

Declarative data (detail)	Paper self-questionnaire
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Quality of life/health perception
<b>Procedures</b>	
Data collection method	Self-administered questionnaire: manual input
Participant monitoring	Yes
Details on monitoring of participants	(Indefinite duration)
Links to administrative sources	Yes
Linked administrative sources (detail)	RNIAM (JO 11 JUNE 2007) French association for the detection and prevention of childhood disabilities
<b>Promotion and access</b>	
<b>Promotion</b>	
Link to the document	<a href="http://tinyurl.com/Pubmed-HYPOTHYROIDIE">http://tinyurl.com/Pubmed-HYPOTHYROIDIE</a>
Description	List of publications in Pubmed
<b>Access</b>	
Terms of data access (charter for data provision, format of data, availability delay)	To be decided if data may be used by academic teams Data may not be used by industrial teams
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only