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	Hypothyroidsm 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

Procedures

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 20007) French association for the detection and prevention of childhood disabilities

Promotion and access

Promotion

Link to the document	http://tinyurl.com/Pubmed-HYPOTHYROIDIE
Description	List of publications in Pubmed

Access

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