

SAGHE - Adult Health Childhood GH

Head :Carel Jean-Claude, CENTRE DE REFERENCE MALADIES ENDOCRINIENNES RARES DE LA CROISSANCE
MINISTERE DE LA SANTÉ. AP-HP

Last update : 08/07/2014 | Version : 2 | ID : 60178

General

Identification

Detailed name Adult Health Childhood GH

Sign or acronym SAGHE

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation
CNIL : 18/07/2007

General Aspects

Medical area Endocrinology and metabolism

Health determinants Occupation

Keywords Socio-professional insertion

Scientific investigator(s) (Contact)

Name of the director Carel

Surname Jean-Claude

Address PARIS

Phone + 33 (0)1 40 03 41 05

Email jean-claude.carel@rdb.aphp.fr

Unit CENTRE DE REFERENCE MALADIES
ENDOCRINIENNES RARES DE LA CROISSANCE
MINISTERE DE LA SANTÉ. AP-HP

Collaborations

Participation in projects, networks and consortia Yes

Funding

Funding status	Public
Details	AFSSAPS, DGS, INCA, FP7
Governance of the database	
Sponsor(s) or organisation(s) responsible	HOPITAL ROBERT DEBRÉ
Organisation status	Public
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 institutions and services
Database recruitment is made on the basis of:	Medication(s) taken
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Retrospective Inclusion cut-off date: 01/12/1997
Database objective	
Main objective	To resolve outstanding issues concerning growth hormone deficiency, Turner's syndrome and patients treated with growth hormone. Secondary objectives: - To explain the frequency and severity of hormonal, metabolic, skeletal, and cardiovascular events during life as well as their determinants. - To identify patient subgroups according to the severity and their phenotypic and/or genetic characteristics in relation to both French molecular genetics laboratories, hospitals and INSERM for developmental pituitary gland abnormalities. - To better understand patient outcome in terms of education, social and professional insertion and psychological impact. - To improve appropriate treatment strategies during childhood and the transition into adulthood. - To reassess the long-

term effectiveness of growth hormone treatment for growth hormone deficiency. Several questions remain outstanding, in addition to high cost, the effectiveness on final height as well as the quality of life for a significant number of patients. - To monitor long-term tolerance with particular focus on tumour risk

Inclusion criteria

Patients treated with recombinant growth hormone in childhood from 1985 to 1997.

Population type

Age

Newborns (birth to 28 days)
Childhood (6 to 13 years)
Adolescence (13 to 18 years)

Population covered

Sick population

Gender

Male
Woman

Geography area

National

Detail of the geography area

20 centres throughout France

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)

01/1985

Size of the database

Size of the database (number of individuals)

[10 000-20 000] individuals

Details of the number of individuals

10 489

Data

Database activity

Data collection completed

Type of data collected

Declarative data
Paraclinical data

Declarative data (detail)

Paper self-questionnaire
Face to face interview

Paraclinical data (detail)

Imaging

Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization Medical/paramedical consultation
Procedures	
Data collection method	Self-administered questionnaire: manual input from a paper questionnaire with double data entry
Participant monitoring	Yes
Details on monitoring of participants	Duration: 30 years
Links to administrative sources	Yes
Linked administrative sources (detail)	CépiDc, RNIAM (MINISTERIAL DECREE OF 4TH MARCH 2008, PUBLISHED IN THE OJ ON 15TH MARCH 2008)
Promotion and access	
Promotion	
Link to the document	http://tinyurl.com/HAL-SAGHE
Description	List of publications in HAL
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=SAGHE+AND+Carel[author]
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.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only