

# SAGHE - Adult Health Childhood GH

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MINISTERE DE LA SANTÉ. AP-HP

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## 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)

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### Collaborations

Participation in projects,  
networks and consortia Yes

### Funding

Funding status	Public
Details	AFSSAPS, DGS, INCA, FP7
<b>Governance of the database</b>	
Sponsor(s) or organisation(s) responsible	HOPITAL ROBERT DEBRÉ
Organisation status	Public
<b>Additional contact</b>	
<b>Main features</b>	
<b>Type of database</b>	
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
<b>Database objective</b>	
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
<b>Procedures</b>	
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)
<b>Promotion and access</b>	
<b>Promotion</b>	
Link to the document	<a href="http://tinyurl.com/HAL-SAGHE">http://tinyurl.com/HAL-SAGHE</a>
Description	List of publications in HAL
Link to the document	<a href="http://www.ncbi.nlm.nih.gov/pubmed/?term=SAGHE+AND+Carel[author]">http://www.ncbi.nlm.nih.gov/pubmed/?term=SAGHE+AND+Carel[author]</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.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only