

# 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
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 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
<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+Carell[author]">http://www.ncbi.nlm.nih.gov/pubmed/?term=SAGHE+AND+Carell[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