

# COHORTE DU RESEAU RHLF - Cohort for French Language Huntington Network

Head :Bachoud-Levi Anne-Catherine, U841 - INSTITUT MONDOR DE RECHERCHE BIOMEDICALE (IMRB)

Last update : 08/07/2014 | Version : 2 | ID : 60079

## General

### Identification

Detailed name Cohort for French Language Huntington Network

Sign or acronym COHORTE DU RESEAU RHLF

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation Accord CNIL

### General Aspects

Medical area Neurology

Health determinants Genetic

Keywords disease progression, Health episodes

### Scientific investigator(s) (Contact)

Name of the director Bachoud-Levi

Surname Anne-Catherine

Phone + 33 (0)1 49 81 23 15

Email anne-catherine.bachoud-levi@hmn.aphp.fr

Unit U841 - INSTITUT MONDOR DE RECHERCHE BIOMEDICALE (IMRB)

Organization INSTITUT MONDOR DE RECHERCHE

### Collaborations

Participation in projects, networks and consortia Yes

### Funding

Funding status	Mixed
Details	GIS - Institut Maladies Rares - Association HUTINGTON FRANCE
<b>Governance of the database</b>	
Sponsor(s) or organisation(s) responsible	APHP
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 carried out as part of an interventional study	No
Additional information regarding sample selection.	Prospective
<b>Database objective</b>	
Main objective	General objective: to improve patient treatment, facilitate and promote epidemiological, clinical, imaging, genetics, biology and therapeutic research
Inclusion criteria	Patients with an identified genetic disease and clinical signs of recent onset.
<b>Population type</b>	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years)
Population covered	Sick population
Gender	Male Woman

Geography area	National
Detail of the geography area	Multicentric cohort throughout France (14 centres)
<b>Data collection</b>	
<b>Dates</b>	
Date of first collection (YYYY or MM/YYYY)	02/2002
<b>Size of the database</b>	
Size of the database (number of individuals)	[1000-10 000[ individuals
Details of the number of individuals	6000
<b>Data</b>	
Database activity	Data collection completed
Type of data collected	Clinical data Declarative data Paraclinical data Biological data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Face to face interview
Paraclinical data (detail)	Imaging
Biological data (detail)	Type of samples taken: Blood count, endocrine evaluation, cholesterol
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality
<b>Procedures</b>	
Participant monitoring	Yes
Details on monitoring of participants	(Indefinite duration)
Links to administrative sources	Yes

## Promotion and access

### Promotion

Link to the document

<http://tinyurl.com/Pubmed-RHL>

Description

List of publications in Pubmed

### Access

Terms of data access (charter for data provision, format of data, availability delay)

Data may be used by academic teams Access in accordance with RHLF charter, acceptance of project by steering committee that evaluates interest, feasibility, and network priorities, followed by information and training for network members during bi-annual plenary meetings in order to achieve the protocol. 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