

COHORTE DU RESEAU RHLF - Cohort for French Language Huntington Network

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

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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
Governance of the database	
Sponsor(s) or organisation(s) responsible	APHP
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 carried out as part of an interventional study	No
Additional information regarding sample selection.	Prospective
Database objective	
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.
Population type	
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)
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	02/2002
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	6000
Data	
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
Procedures	
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