

CADASIL - CADASIL patient cohort

Head :Chabriat Hugues, CERVCO CENTRE DE RÉFÉRENCES POUR LES MALADIES RARES DES VAISSEaux DU CERVEAU ET DE L'OEIL, HOPITAL LARIBOISIÈRE

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General	
Identification	
Detailed name	CADASIL patient cohort
Sign or acronym	CADASIL
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	Occupation
Keywords	cognitive decline, mobility impairment, migraine, ischaemic stroke, epileptic seizure, Health episodes, apathy, hospitalisation, health system
Scientific investigator(s) (Contact)	
Name of the director	Chabriat
Surname	Hugues
Address	75010 PARIS
Phone	+ 33 (0)1 49 95 25 95
Email	hugues.chabriat@lrb.aphp.fr
Unit	CERVCO CENTRE DE RÉFÉRENCES POUR LES MALADIES RARES DES VAISSEaux DU CERVEAU ET DE L'OEIL, HOPITAL LARIBOISIÈRE
Organization	APHP
Collaborations	

Funding	
Funding status	Mixed
Details	PHRC, Centre de maladies rares, dons association ARNEVA, Association CADASIL France (familles)
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
Database objective	
Main objective	General objective: prospective study of patients with Notch 3 gene mutation thought to cause CADASIL: research into prognostic factors and useful markers for preventative treatment trial. Secondary objectives: - To determine clinical-radiological correlations - Modifying factors of clinical phenotype and MRI studies - Prognostic and progressive factors - Clinical phenotype variability - Natural history of disease
Inclusion criteria	Adult patients with Notch 3 genetic mutation thought to cause CADASIL
Population type	
Age	Great age (80 years and more)
Population covered	Sick population

Gender	Male Woman
Geography area	Local
French regions covered by the database	Île-de-France
Detail of the geography area	Lariboisière Hospital, Paris
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	04/2006
Date of last collection (YYYY or MM/YYYY)	12/2007
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	250
Data	
Database activity	Data collection completed
Type of data collected	Clinical data Paraclinical data Biological data
Clinical data (detail)	Medical registration
Paraclinical data (detail)	Carotid Doppler ultrasound and MRI with measurement or calculation of total lacunar infarcts and white matter hyperintensities, brain volume, average circulation and number of microbleeds
Biological data (detail)	Biological assessment
Presence of a biobank	No
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	

Participant monitoring	Yes
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=CADASIL+AND+cohort+AND+apathy+AND+Chabriat+H[Author]
Description	List of publications in Pubmed
Access	
Terms of data access (charter for data provision, format of data, availability delay)	To be decided by scientist in charge
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only