

DMLA 2007 - Hereditary Retinal Dystrophy 2007

Head :Sahel José-Alain, UMR592 UPMC/CHNO DES XV-XX/INSERM
BENCHABOUNE , INSERM CIC 503 CHNO DES XV

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General	
Identification	
Detailed name	Hereditary Retinal Dystrophy 2007
Sign or acronym	DMLA 2007
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CPP 11 décembre 2006, n° IDRCD 2006 -a00347-44
General Aspects	
Medical area	Ophthalmology Radiology and medical imaging
Health determinants	Genetic
Others (details)	Hereditary retinal dystrophy
Keywords	Visual function, morphometric data, retina, impact, quality of life, assessment, disability
Scientific investigator(s) (Contact)	
Name of the director	Sahel
Surname	José-Alain
Address	75012 PARIS
Phone	+ 33 (0)1 40 02 14 04
Email	j-sahel@quinze-vingts.fr
Unit	UMR592 UPMC/CHNO DES XV-XX/INSERM
Organization	CHNO DES
Name of the director	BENCHABOUNE

Address	75012 PARIS
Phone	+ 33 (01) 40 02 14 39
Email	mb@cicoph.org
Unit	INSERM CIC 503 CHNO DES XV
Organization	INSERM
Collaborations	
Participation in projects, networks and consortia	Yes
Funding	
Funding status	Mixed
Details	ANR, FRM
Governance of the database	
Sponsor(s) or organisation(s) responsible	CHNO DES QUINZE-VINGTS
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Study databases
Study databases (details)	Case control 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 Other bodies active in creating this cohort: CHU, CHG
Database objective	
Main objective	General objective: to identify genetic predisposition factors Secondary objectives: - to study

morphofunctional correlations - to research predictive signs of progression.

Inclusion criteria	Individuals with hereditary retinal dystrophy Related individuals
Population type	
Age	Adulthood (19 to 24 years) Adulthood (25 to 44 years) Adulthood (45 to 64 years) Elderly (65 to 79 years) Great age (80 years and more)
Population covered	Sick population
Gender	Male Woman
Geography area	National
Detail of the geography area	Multicentric cohort throughout France
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	11/2007
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1500
Data	
Database activity	Data collection completed
Type of data collected	Declarative data Paraclinical data Biological data
Declarative data (detail)	Paper self-questionnaire Face to face interview
Paraclinical data (detail)	Imaging, visual acuity, visual field assessment, colour vision examination, electroretinography

Biological data (detail)	Type of samples taken: Blood
Presence of a biobank	Yes
Contents of biobank	DNA
Details of biobank content	DNA bank
Health parameters studied	Health event/morbidity Health event/mortality Quality of life/health perception
Procedures	
Data collection method	Self-administered questionnaire: manual input Interview: manual input Biological analysis: manual input
Participant monitoring	Yes
Details on monitoring of participants	(Indefinite duration)
Links to administrative sources	No
Promotion and access	
Promotion	
Link to the document	http://bjo.bmj.com/content/82/9/996.long
Access	
Terms of data access (charter for data provision, format of data, availability delay)	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