DMLA 2004 - Hereditary Retinal Dystrophy 2004

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General

Identification

Detailed name	Hereditary Retinal Dystrophy 2004
Sign or acronym	DMLA 2004
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL

General Aspects

Medical area	Ophthalmology Radiology and medical imaging
Health determinants	Genetic
Keywords	visual function, Health episodes, morphometric data, retina, impact, quality of life, assessment, disability

Scientific investigator(s) (Contact)

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Collaborations

Funding

Funding status	Mixed
Details	ANR, Inserm, CHNO 15-20, Communauté Européenne, Ministère de la Recherche et de l'Enseignement Supérieur, Ministère de la Santé, Fondation FIGHTING BLINDNESS (USA), FONDATION VOIRE ET ENTENDRE, FONDATION POUR LA RECHERCHE MEDICALE

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 study genotype-phenotype

	correlations Secondary objectives: - to study morphofunctional correlations - to identify new functional or morphological markers - 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 (13 centres)
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	10/2004
Size of the database	
Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1844
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)	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	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