## DMLA 2004 - Hereditary Retinal Dystrophy 2004

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Last update : 08/06/2014 | Version : 1 | ID : 60094

| 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 <br> 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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| Organization | INSERM |
| 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 No out as part of an interventional study

Additional information regarding sample selection.

Prospective Other bodies active in creating this cohort: CHU, CHG

## Database objective

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) <br> Adulthood (25 to 44 years) <br> Adulthood (45 to 64 years) <br> Elderly (65 to 79 years) <br> 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/YYY) | 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 | $\underline{\text { http://bjo.bmj.com/content/82/9/996.long }}$ |
| 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 |

