

ARVD - Genetic Study of Arrhythmogenic Right Ventricular Dysplasia

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General

Identification

Detailed name Genetic Study of Arrhythmogenic Right Ventricular Dysplasia

Sign or acronym ARVD

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation Accord CNIL, accord CPP

General Aspects

Medical area Cardiology

Health determinants Genetic

Others (details) Right ventricular dysplasia

Keywords unscheduled hospitalisation, dysplasia, cardiomyopathy, Health episodes, death

Scientific investigator(s) (Contact)

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Unit Centre de référence, CHU Pitié-Salpêtrière, Paris

Organization Assistance Publique - Hôpitaux de

Collaborations

Funding

Funding status Public

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|--|--|
| Details | Programme hospitalier de recherche clinique |
| Governance of the database | |
| Sponsor(s) or organisation(s) responsible | Assistance Publique - Hôpitaux de Paris |
| 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. | Diagnosis was established according to international standards including results from bi-ventricular contrast angiography scan or cardiac MRI. |
| Database objective | |
| Main objective | General objective: The aim of this project is to investigate the genetic and phenotypic aspects of the disease and determine the role of genetic testing in clinical practice: diagnostic and prognostic value. Secondary objective. |
| Inclusion criteria | All patients with ARVD regardless of age and family background. All first degree relations over 10 years old are included. |
| Population type | |
| Age | Childhood (6 to 13 years) Adolescence (13 to 18 years) 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 |

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|--|---|
| Gender | Male Woman |
| Geography area | National |
| Detail of the geography area | Pitié Salpêtrière |
| Data collection | |
| Dates | |
| Date of first collection (YYYY or MM/YYYY) | 2002 |
| Date of last collection (YYYY or MM/YYYY) | 2008 |
| Size of the database | |
| Size of the database (number of individuals) | < 500 individuals |
| Details of the number of individuals | 350 (128 familles/families) |
| Data | |
| Database activity | Data collection completed |
| Type of data collected | Clinical data Declarative data Paraclinical data |
| Clinical data (detail) | Direct physical measures |
| Declarative data (detail) | Face to face interview |
| Paraclinical data (detail) | Bi-ventricular angiography scan with contrast, ECG, echocardiography, ECG-HA, Holter-ECG, stress test, cardiac MRI. |
| Presence of a biobank | No |
| Health parameters studied | Health event/morbidity Health event/mortality Others |
| Other (detail) | Etiology/genetics Mortality only with no Health episodes |
| Procedures | |

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|---------------------------------------|------------------------------|
| Data collection method | ----- |
| Participant monitoring | Yes |
| Details on monitoring of participants | Average follow-up: 36 months |
| Links to administrative sources | No |

Promotion and access

Promotion

| | |
|----------------------|---|
| Link to the document | http://europace.oxfordjournals.org/content/11/3/379.long |
| Link to the document | http://europace.oxfordjournals.org/content/12/6/861.long |
| Link to the document | http://heart.bmj.com/content/97/10/844.full.pdf+html |
| Link to the document | http://www.internationaljournalofcardiology.com/article/S0167-5273%2812%2900859-5/fulltext |
| Link to the document | http://europace.oxfordjournals.org/content/early/2013/07/12/europace.eut224.long |
| Link to the document | http://www.cardiogen.aphp.fr |

Access

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|---|--|
| Terms of data access (charter for data provision, format of data, availability delay) | Pathology report, authorised sport activity: on reference centre website: www.cardiogen.aphp.fr |
| Access to aggregated data | Access on specific project only |
| Access to individual data | Access on specific project only |