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)

Name of the director	Charron
Surname	Philippe
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Unit	Centre de référence, CHU Pitié-Salpêtrière, Paris
Organization	Assistance Publique - Hôpitaux de

Collaborations

Funding

Funding status	Public

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

Gender	Male Woman
Geography area	National
Detail of the geography area	Pitié Salpétrière

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

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

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