AMYLO-STUDY - Prevalence of Transthyretin Amyloidosis in Hypertrophic Cardiomyopathy

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Last update : 05/12/2015 | Version : 1 | ID : 8655

General

Identification

Detailed name	Prevalence of Transthyretin Amyloidosis in Hypertrophic Cardiomyopathy
Sign or acronym	AMYLO-STUDY
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL

General Aspects

Medical area	Cardiology
Health determinants	Genetic
Keywords	heredity, under-diagnosis, mutation, prevalence

Scientific investigator(s) (Contact)

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Collaborations

Funding

Funding status	Private
Details	French Cardiology Society.

Governance of the database

Sponsor(s) or organisation(s) responsible	Société Française de Cardiologie
Organisation status	Private

Additional contact

Main features

Type of database

Type of database	Study databases
Study databases (details)	Not-repeated cross-sectional studies (except case

	control studies)
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

Database objective

Main objective	To define the prevalence of TTR amyloidosis in a large population of patients attending the CMH.
Inclusion criteria	- Aged 18 years and over; - Cardiomyopathy defined by an ultrasound thickness of the left ventricle greater than or equal to13 mm if familial form, or greater than or equal to 15 mm if sporadic form; - Patients with a signed consent authorising the specific blood test for genetic sequencing to look for an abnormal TTR gene. Exclusion criteria: - Significant AS (less than or equal to 1cm2); - Patients with a cardiomyopathy diagnosis (sarcomeric HCM, Fabry disease, etc.) or related already diagnosed. Patients included in the REMY registry (Hypertrophic Cardiomyopathy Registry) may also be included in the amyloid-STUDY. Inclusion criteria are very similar. Some additional data will need to be completed on the page corresponding to the registry.

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	France

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	05/2012
Date of last collection (YYYY or MM/YYYY)	04/2014

Size of the database

Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	Objective:260. 298 patients enrolled on 30/04/2014.

Data

Database activity	Current data collection
Type of data collected	Clinical data Declarative data Paraclinical data Biological data
Clinical data (detail)	Medical registration
Details of collected clinical data	Weight, height, macroglossia, monoclonal gammopathy, carpal tunnel surgical history, EMG, dysautonomia, gastroparesis.
Declarative data (detail)	Paper self-questionnaire Face to face interview
Details of collected declarative data	Family and personal history, current or completed treatment.
Paraclinical data (detail)	Etiology, MRI, ECG, biopsies.
Biological data (detail)	BNP, NT-Pro BNP, troponin, CPK, creatinine, haemoglobin, high-sensitivity CRP, iron level, TSH, serum calcium, serum protein electrophoresis, ?-galactosidase A assay, genotyping.
Presence of a biobank	Yes
Contents of biobank	Whole blood
Details of biobank content	Blood.

Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	e-CRF.
Participant monitoring	No
Links to administrative sources	No
Promotion and access	
Promotion	
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Contact the scientist in charge.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only