

MARFAN - Patients with Marfan Syndrome or Related Conditions

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INSERM U 793 AP-HP

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General	
Identification	
Detailed name	Patients with Marfan Syndrome or Related Conditions
Sign or acronym	MARFAN
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	Accord CNIL : 26/10/2007
General Aspects	
Medical area	Cardiology
Health determinants	Genetic Occupation
Others (details)	Marfan syndrome or related conditions
Keywords	aortic dissection, surgery, mitral valve, crystalline, orthopaedics, Health episodes
Scientific investigator(s) (Contact)	
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Unit	CENTRE DE REFERENCE SYNDROME DE MARFAN ET APPARENTES INSERM U 698 INSERM U 793 AP-HP
Organization	INSERM

Collaborations	
Participation in projects, networks and consortia	Yes
Funding	
Funding status	Public
Details	GIS MALADIES RARES, SOCIETE FRANÇAISE DE CARDIOLOGIE/ FEDERATION FRANÇAISE DE CARDIOLOGIE DHOS DANS LE CADRE DU FINANCEMENT DU CENTRE DE REFERENCE
Governance of the database	
Sponsor(s) or organisation(s) responsible	INSERM - Institut National de la Santé et de la Recherche Médicale
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.	Inclusion method: Prospective Other bodies active in creating this cohort: CHU, SPECIALIST CENTRES FOR MARFAN SYNDROME AND RELATED CONDITIONS Inclusion cut-off date: indefinite
Database objective	
Main objective	General objective: To assess predictive factors of aortic dissection in patients with Marfan syndrome in order to determine parameters for aortic surgical treatment that are poorly defined at present. Secondary objectives: - To describe modern representation of patients with Marfan syndrome - to investigate intrafamilial variability - To investigate

the importance of gender, treatment benefits and changes in treatment over time - To study factors of aortic dilation.

Inclusion criteria

Adults attending specialist consultation for Marfan syndrome and related conditions

Population type

Age

Adulthood (19 to 24 years)
Adulthood (25 to 44 years)
Adulthood (45 to 64 years)

Population covered

Sick population

Gender

Male
Woman

Geography area

National

Detail of the geography area

Multicentric cohort (7 centres) throughout France and subsequently Germany and Belgium

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)

10/1996

Size of the database

Size of the database (number of individuals)

[500-1000[individuals

Details of the number of individuals

827

Data

Database activity

Data collection completed

Type of data collected

Paraclinical data
Biological data

Paraclinical data (detail)

Imaging

Biological data (detail)

Type of samples taken: Additional tubes required for study for samples taken while in care

Presence of a biobank

Yes

Contents of biobank	Serum Plasma DNA
Details of biobank content	Serum bank, Plasma bank, DNA bank
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	Interview: Direct input Clinical examination: Direct input Biological analysis: Handwritten (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://www.ncbi.nlm.nih.gov/pubmed/24254191
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/24254191
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/24008997
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/23810486
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/23506379
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/22440060
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/22424326
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/22772371
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Data may be used by academic teams Contractual access Data may be used by industrial teams: to be decided Access determined on a case by case basis
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only