CRB-REFGENSEP - Biological Resources Centre (BRC) of The French Multiple Sclerosis Genetics Group

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General

Identification

Detailed name	Biological Resources Centre (BRC) of The French Multiple Sclerosis Genetics Group
Sign or acronym	CRB-REFGENSEP
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL no. 00239 (05/02/2001), no. DC-2008-539, no. AC-2008-548.

General Aspects

Medical area	Neurology
Health determinants	Genetic
Keywords	genetic and clinical criteria, patients

Scientific investigator(s) (Contact)

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Name of the director	Rebeix
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Organization	INSERM

Collaborations

Funding

Funding status	Mixed
Details	INSERM, GIS-IBISA, ARSEP, AFM

Governance of the database

Sponsor(s) or organisation(s) responsible	INSERM
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Study databases
Study databases (details)	Longitudinal study (except cohorts)
Database recruitment is carried out as part of an interventional study	No
Additional information regarding sample selection.	Campaign to obtain samples from 23 French hospital centres.

Database objective

Main objective	To make a collection of DNA and cells from patients with multiple sclerosis and their relatives that can be accessed by the scientific community (any team on request).
Inclusion criteria	Adult patients with multiple sclerosis and their relatives.

Population type

Age	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)
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)	1996

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	6,000

Data

Database activity	Current data collection
Type of data collected	Clinical data Biological data Administrative data
Clinical data (detail)	Medical registration
Biological data (detail)	HLA (human leukocyte antigen) genotype and SNP (single-nucleotide polymorphism) genotype.
Administrative data (detail)	Civil status, address when sample was taken.
Presence of a biobank	Yes
Contents of biobank	Blood cells isolated Cell lines DNA

Details of biobank content	Biological samples are available to any research team on request. This request will be assessed by the CRB-REFGENSP scientific committee
Health parameters studied	Health event/morbidity Health event/mortality

Procedures

Data collection method	The following is collected during the clinical examination in a REFGENSEP network collection centre: age of disease onset, disease type and disability (EDSS/Expanded Disability Status Scale). Genetic annotations are collected during collaborations with research teams.
Participant monitoring	Yes
Details on monitoring of participants	Disease progression, in terms of disability, is monitored during consultations.
Links to administrative sources	No

Promotion and access

Promotion

Access

Terms of data access (charter for data provision, format of data, availability delay)	Send written request to isabelle.rebeix@upmc.fr.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only