3GENSSC - GFRS- 3 GENERATIONS-SCLERODERMA

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General

Identification

Detailed name	GFRS- 3 GENERATIONS-SCLERODERMA
Sign or acronym	3GENSSC
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	N°de protocole RBM-04-60 (20-09-2004) et collection N°DC-2008-327 (2008)

General Aspects

Health determinants	Genetic
Keywords	HLA genotyping, family members, compatibility, microchimerism, autoimmunity markers

Scientific investigator(s) (Contact)

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Surname	Nathalie
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Organization	INSERM - Institut National de la Santé et de la Recherche
Name of the director	Farge
Surname	Dominique

Collaborations

Funding

Funding status	Mixed
Details	PRO-A INSERM

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)	Longitudinal study (except cohorts)
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.	New subjects are enrolled from active patient files monitored by recruitment centres

Database objective

Main objective	To form the first French cohort of 3 generations of subjects who have scleroderma (SSc). To carry out HLA (human leukocyte antigen) genotyping for all subjects and family members so as to understand the relationship between HLA compatibility between SSc patients with and members of their family and to further study the role of microchimerism and maternal-foetal compatibility. To continue studies previously undertaken on the preponderance of autoimmune disease in women and to research new markers of SSc on a larger number of subjects.
Inclusion criteria	Women whose parents are still alive and whose children wish to participate in the study.

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	France

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)	10/2004

Size of the database

Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	400

Data

Database activity	Current data collection
Type of data collected	Clinical data
Clinical data (detail)	Direct physical measures
Presence of a biobank	Yes
Contents of biobank	Whole blood
Details of biobank content	Whole blood from subjects will be collected in EDTA vacutainer tubes. An aliquot of 350 ul will be retained and DNA will be extracted using a kit (EZ1 DNA Blood Kit, Qiagen, Hilden, Germany) on a BIOROBOT EZ1 according to instructions.

Health parameters studied	Health event/morbidity Health event/mortality

Procedures

Data collection method	Family members will be contacted by post by a Clinical Research representative (research engineer). To facilitate geographic difficulties for dispersed families, mouth wash will be sent to collect buccal cells for DNA extraction, or an appointment will be made in accordance with the subject in an analysis laboratory close to the subject's home.
Participant monitoring	Yes
Links to administrative sources	No

Promotion and access

Promotion

Access

Terms of data access (charter for data provision, format of data, availability delay)	To be defined
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only