HSPronostic - Physiopathology and Prognostic Biomarkers for Henoch-Schönlein Purpura

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General

Identification

Detailed name	Physiopathology and Prognostic Biomarkers for Henoch-Schönlein Purpura
Sign or acronym	HSPronostic
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL DR-2011-494

General Aspects

Medical area	Immunology Internal medicine Rare diseases Urology, andrology and nephrology
Health determinants	Genetic
Others (details)	Henoch-Schönlein purpura
Keywords	Henoch-Schönlein purpura, physiopathological markers, prognostic markers, renal impairment, phenotype, diagnosis

Scientific investigator(s) (Contact)

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Unit	Unité U699 - Equipe « Immunorécepteurs et Immunopathologie rénale »
Organization	INSERM - Institut National de la Santé et de la Recherche
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Organization	APHP

Collaborations

Funding

Funding status	Public
Details	Inserm/DGOS (direction générale de l'offre de soins)

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.	Recruitment by physicians from the following services: paediatrics and adult services, emergency services, internal medicine, dermatology and nephrology.
Database objective	
Main objective	To evaluate the biological profile of patients with skin Henoch-Schönlein purpura according to the presence or absence of renal impairment. To identify specific genetic susceptibility and biomarkers that can predict poor renal impairment prognosis at 1 year.
Inclusion criteria	Patients with Henoch-Schönlein purpura confirmed by skin lesions
Population type	
Age	Infant (28 days to 2 years) Early childhood (2 to 5 years) 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)	2011
Date of last collection (YYYY or MM/YYYY)	2013
Size of the database	
Size of the database (number of individuals)	< 500 individuals

Details of the number of individuals	120
Data	
Database activity	Current data collection
Type of data collected	Clinical data Paraclinical data Biological data
Clinical data (detail)	Direct physical measures Medical registration
Paraclinical data (detail)	Skin and renal biopsy
Biological data (detail)	At J0 and M12, creatinine, proteinuria rate, urinary sediment, FBC
Presence of a biobank	Yes
Contents of biobank	Serum Plasma Fluids (saliva, urine, amniotic fluid, ?) DNA
Details of biobank content	DNA bank, cell bank, serum bank
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	Anonymised clinical record completed by recruiting physician
Participant monitoring	Yes
Details on monitoring of participants	At least to one-year. Proposal of up to 3 years.
Links to administrative sources	No
Promotion and access	
Promotion	
Access	
Terms of data access (charter for data provision, format of data, availability delay)	Publications

Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only