

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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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