

KAWA-NET - Registry on Kawasaki Disease

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General

Identification

Detailed name Registry on Kawasaki Disease

Sign or acronym KAWA-NET

CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation

CNIL

General Aspects

Medical area
Cardiology
Pediatrics
Rare diseases
Rheumatology

Pathology (details) Kawasaki disease

Keywords kawanet, heart complications, Kawasaki, treatment

Scientific investigator(s) (Contact)

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Name of the director	Darce Bello
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Organization	Kremlin-Bicêtre University Hospital (AP-HP)
Collaborations	
Funding	
Funding status	Public
Details	PHRC 2009
Governance of the database	
Sponsor(s) or organisation(s) responsible	Paris Public Hospitals (AP-HP)
Organisation status	Public
Additional contact	
Main features	
Type of database	
Type of database	Morbidity registers
Database objective	
Main objective	Kawanet is a clinical and biological data repository aimed to define the epidemiological characteristics of Kawasaki disease in the French population; to research risk factors for cardiac complications or resistance to standard treatment and to participate in genomic studies in an international consortium.
Inclusion criteria	Patients diagnosed with KD in a French hospital were prospectively and retrospectively included between 01/2011 and 03/2014. Data was stored on a secure electronic database (Cleanweb). A DNA-trio collection was carried out among consenting families.
Population type	
Age	Newborns (birth to 28 days)

Infant (28 days to 2 years)
Early childhood (2 to 5 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) 2011

Date of last collection (YYYY or MM/YYYY) 2014

Size of the database

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

Details of the number of individuals 401

Data

Database activity Data collection completed

Type of data collected Clinical data

Clinical data (detail) Direct physical measures

Details of collected clinical data Sex; age; origin; symptoms; heart complications; treatment

Presence of a biobank Yes

Contents of biobank DNA

Details of biobank content A DNA-trio collection was carried out among consenting families.

Health parameters studied Health event/morbidity
Health care consumption and services

Care consumption (detail) Medicines consumption

Procedures

Participant monitoring No

Links to administrative sources No

Promotion and access

Promotion

Link to the document <http://mediatheque.larhumatologie.fr/mediatheque/media.aspx?mediaId=6721&channel=5730>

Access

Terms of data access (charter for data provision, format of data, availability delay) Contact the scientist in charge.

Access to aggregated data Access on specific project only

Access to individual data Access on specific project only