KAWA-NET - Registry on Kawasaki Disease

Head :Kone-Paut Isabelle
Piram Maryam
Darce Bello Martha

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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)

Name of the director	Kone-Paut
Surname	Isabelle
Phone	+33 (0)1 45 21 32 47
Email	isabelle.kone-paut@bct.aphp.fr
Organization	Kremlin-Bicêtre University Hospital (AP-HP)
Name of the director	Piram
Surname	Maryam
Email	maryam.piram@bct.aphp.fr

Organization	Bicêtre University Hospital
Name of the director	Darce Bello
Surname	Martha
Email	martha.darce@bct.aphp.fr
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