

PED-BD - Development of an Early Diagnosis Tool for Behcet's Disease in Childhood for International Epidemiological Studies and the Formation of a DNA Bank

Head :Koné-Paut Isabelle, CENTRE NATIONAL DE REFERENCE DES MALADIES AUTO-INFLAMMATOIRES.
RHEUMATOLOGIE PEDIATRIQUE. SERVICE DE PEDIATRIE GENERALE. CHU BICETRE
Tran Tu-Anh, CENTRE NATIONAL DE REFERENCE DES MALADIES AUTO-INFLAMMATOIRES.
RHEUMATOLOGIE PEDIATRIQUE. SERVICE DE PEDIATRIE GENERALE. CHU BICETRE
Darce Bello Martha, CENTRE NATIONAL DE REFERENCE DES MALADIES AUTO-INFLAMMATOIRES.
RHEUMATOLOGIE PEDIATRIQUE. SERVICE DE PEDIATRIE GENERALE. CENTRE NATIONAL DE REFERENCE
DES MALADIES AUTO-INFLAMMATOIRES. RHEUMATOLOGIE PEDIATRIQUE. SERVICE DE PEDIATRIE
GENERALE.

Last update : 08/08/2014 | Version : 2 | ID : 60194

General	
Identification	
Detailed name	Development of an Early Diagnosis Tool for Behcet's Disease in Childhood for International Epidemiological Studies and the Formation of a DNA Bank
Sign or acronym	PED-BD
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL : 14/10/2008
General Aspects	
Medical area	Internal medicine
Health determinants	Genetic
Keywords	symptoms, Recurrent oral aphthosis (ROA), genital ulceration (GU), erythema nodosum, folliculitis, pustulous/acneiform lesions, positive pathergy test, uveitis, venous/arterial thrombosis
Scientific investigator(s) (Contact)	
Name of the director	Koné-Paut
Surname	Isabelle
Address	94275 LE KREMLIN BICÊTRE

Phone	+33 (0)1 45 21 63 08
Email	isabelle.kone-paut@bct.aphp.fr
Unit	CENTRE NATIONAL DE REFERENCE DES MALADIES AUTO-INFLAMMATOIRES. RHEUMATOLOGIE PEDIATRIQUE. SERVICE DE PEDIATRIE GENERALE. CHU BICETRE

Name of the director	Tran
Surname	Tu-Anh
Address	94275 LE KREMLIN BICÊTRE
Phone	+33 (0)1 45 21 32 45
Email	tu-anh.tran@bct.aphp.fr
Unit	CENTRE NATIONAL DE REFERENCE DES MALADIES AUTO-INFLAMMATOIRES. RHEUMATOLOGIE PEDIATRIQUE. SERVICE DE PEDIATRIE GENERALE. CHU BICETRE

Name of the director	Darce Bello
Surname	Martha
Address	94275 LE KREMLIN BICÊTRE
Phone	+33 (0)1 45 21 63 08
Email	martha.darce@bct.aphp.fr
Unit	CENTRE NATIONAL DE REFERENCE DES MALADIES AUTO-INFLAMMATOIRES. RHEUMATOLOGIE PEDIATRIQUE. SERVICE DE PEDIATRIE GENERALE. CENTRE NATIONAL DE REFERENCE DES MALADIES AUTO-INFLAMMATOIRES. RHEUMATOLOGIE PEDIATRIQUE. SERVICE DE PEDIATRIE GENERALE.

Collaborations

Participation in projects, networks and consortia	Yes
--	-----

Funding

Funding status	Public
----------------	--------

Details	APHP/Programme hospitalier de recherche clinique.
---------	---

Governance of the database	
Sponsor(s) or organisation(s) responsible	APHP
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	Yes
Details	Performed at individual level
Additional information regarding sample selection.	Prospective. Inclusion cut-off date not determined.
Database objective	
Main objective	To define early diagnostic criteria for Behcet's Disease for patients under 16 years old.
Inclusion criteria	Recurrent oral aphthosis (ROA) associated with at least one of these symptoms: genital ulceration (GU), erythema nodosum, folliculitis, pustulous/acneiform lesions, positive pathergy test, uveitis, venous/arterial thrombosis, family history of Maladie de Behcet
Population type	
Age	Childhood (6 to 13 years) Adolescence (13 to 18 years)
Population covered	Sick population
Gender	Male Woman
Geography area	International

Detail of the geography area	32 centres: France, UK, Italy, Switzerland, Germany, Japan, Saudi Arabia, Iran, Turkey, Egypt and Morocco.
Data collection	
Dates	
Date of first collection (YYYY or MM/YYYY)	03/2008
Date of last collection (YYYY or MM/YYYY)	03/2012
Size of the database	
Size of the database (number of individuals)	< 500 individuals
Details of the number of individuals	110
Data	
Database activity	Current data collection
Type of data collected	Clinical data Declarative data
Clinical data (detail)	Direct physical measures Medical registration
Declarative data (detail)	Face to face interview
Presence of a biobank	Yes
Contents of biobank	Blood cells isolated DNA
Details of biobank content	DNA bank, cell bank
Health parameters studied	Health event/morbidity Health event/mortality
Procedures	
Data collection method	Interviews: manual input from a paper questionnaire. Clinical examinations: handwritten. Biological analysis: handwritten.
Participant monitoring	Yes

Details on monitoring of participants	Indefinite duration
Links to administrative sources	Yes
Linked administrative sources (detail)	CLEAN WEB
Promotion and access	
Promotion	
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/?term=PED-BD
Description	List of publications in Pubmed
Access	
Terms of data access (charter for data provision, format of data, availability delay)	- Data may be used by academic teams; - To be decided if data may be used by industrial teams.
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only