

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
---------------------------	---------------------------------