CRMW - National Reference Centre for Von Willebrand Disease

Head :Veyradier Agnès, Service d'Hématologie biologique, Hôpitaux Universitaires Paris Sud, site Antoine Béclère, Clamart

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General

Identification

Detailed name	National Reference Centre for Von Willebrand Disease
Sign or acronym	CRMW
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL 1245379

General Aspects

Medical area	Hematology Rare diseases
Health determinants	Genetic Occupation Social and psychosocial factors
Others (details)	Von Willebrand disease, haemorrhagic disease
Keywords	Haemostasis - von Willebrand factor

Scientific investigator(s) (Contact)

Name of the director	Veyradier
Surname	Agnès
Address	Hématologie biologique, Hôpitaux Universitaires Paris Sud, site Antoine Béclère, 157 rue de la Porte de Trivaux, 92140 Clamart
Phone	+ 33 (0)1 45 37 43 05
Email	agnes.veyradier@abc.aphp.fr
Unit	Service d'Hématologie biologique, Hôpitaux Universitaires Paris Sud, site Antoine Béclère,

	Clamart
Organization	Assistance Publique - Hôpitaux de

Collaborations

Funding

Funding status	Mixed
Details	Le CRMW a été labellisé en 2006 par le ministère de la santé dans le cadre du Plan National Maladies Rares 1 (PNMR1). Les postes obtenus sont financés par la DHOS (Direction de l'Hospitalisation et de l'Offre de Soins) ou DGS (Direction Générale de la Santé).

Governance of the database

Sponsor(s) or organisation(s) responsible	Hôpitaux Universitaires Paris Sud
Organisation status	Public
Sponsor(s) or organisation(s) responsible	Centre Hospitalier Régional Universitaire de Lille
Organisation status	Public

Additional contact

Main features

Type of database

Type of database	Morbidity registers
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.	Subjects are selected based on phenotypic inclusion criteria (von Willebrand factor plasma levels). There is no random selection.

Database objective

Main objective	Epidemiology of different types and sub-types of von Willebrand Disease in France

Inclusion criteria	Patients with von Willebrand Disease monitored by hospitals in France

Population type

Age	Newborns (birth to 28 days) 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)	2007
Date of last collection (YYYY or MM/YYYY)	2013

Size of the database

Size of the database (number of individuals)	[1000-10 000[individuals
Details of the number of individuals	1289 patients (1008 familles/families)

Data

Database activity	Current data collection
Type of data collected	Biological data
Biological data (detail)	Von Willebrand factor phenotypic and genotypic data

Presence of a biobank	Yes
Contents of biobank	Whole blood Plasma DNA
Details of biobank content	Plasma and DNA
Health parameters studied	Health event/morbidity Health event/mortality Health care consumption and services Quality of life/health perception
Care consumption (detail)	Hospitalization Medical/paramedical consultation Medicines consumption

Procedures

Data collection method	A physician and clinical research associate from the National Reference Centre for von Willebrand Disease (CRMW) continuously gather data as patients are included. Data are recorded electronically in an Excel file registered with the CNIL (Commission Nationale d'Informatiquess et des Libertés).
Participant monitoring	Yes
Links to administrative sources	No

Promotion and access

Promotion

Access

Terms of data access (charter for data provision, format of data, availability delay)	Publications Only physicians and CRA from the CRMQ have access to data. This prerequisite is clearly stated in the CNIL agreement.
Access to aggregated data	Access on specific project only
Access to individual data	No access