

EUROCORD - Follow-up of a cohort of patients who received umbilical cord blood transplantation with malignant and non-malignant haematological diseases

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Last update : 08/20/2014 | Version : 1 | ID : 60097

General	
Identification	
Detailed name	Follow-up of a cohort of patients who received umbilical cord blood transplantation with malignant and non-malignant haematological diseases
Sign or acronym	EUROCORD
CNIL registration number, number and date of CPP agreement, AFSSAPS (French Health Products Safety Agency) authorisation	CNIL: 01/07/2001
General Aspects	
Medical area	Cardiology Hematology
Health determinants	Iatrogenic
Others (details)	Haemopathy
Keywords	engraftment, reaction, graft against the host, acute, chronic, Health episodes, relapse, mortality
Scientific investigator(s) (Contact)	
Name of the director	Rocha
Surname	Vanderson
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Unit	EUROCORD- OFFICE DE RECHERCHE CLINIQUE EN HEMATOLOGIE ET IMMUNODEFICIENCE

Organization	INSTITUT UNIVERSITAIRE D' HEMATOLOGIE- UNIVERSITE DE PARIS
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Collaborations

Participation in projects, networks and consortia	Yes
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Funding

Funding status	Public
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Details	DRC-APHP, ABM
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Governance of the database

Sponsor(s) or organisation(s) responsible	INSTITUT UNIVERSITAIRE D'HEMATOLOGIE- EUROCORD/ DBIM
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Organisation status	Public
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Additional contact

Main features

Type of database

Type of database	Study databases
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Study databases (details)	Cohort study
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Database recruitment is carried out by an intermediary	A selection of health institutions and services
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Database recruitment is made on the basis of:	Another treatment or procedure
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Database recruitment is carried out as part of an interventional study	No
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Additional information regarding sample selection.	Inclusion method: Prospective Other bodies active in creating this cohort: STEM CELL TRANSPLANTATION CENTRES AND UMBILICAL CORD BLOOD BANKS LOCATED IN FRANCE, EUROPE AND INTERNATIONALLY
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Database objective

Main objective	General objective: To collect clinical data for new transplant patients and updating cohort follow-up for analysis of prognostic factors from
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transplantation results in Europe and globally with one or two units of cord blood from umbilical cord blood banks located in France, Europe or internationally. Secondary Objective: To improve data recovery through the creation of an electronic system for collecting data online for cord blood banks in order to facilitate the flow of information from these banks and allow the retrieval of non-analysed to date. To restructure the current information system, notably thanks to the development of new technologies for database management and the application of international standards. To develop a network of electronic communication with other existing databases with PROMISE (EBMT register for bone marrow transplants), Netcord (bank network), the NMDP and CIBMTR in the USA.

Inclusion criteria

All patients who received one or two units of umbilical cord blood in Europe or international patients who received one or two units of cord blood from European banks

Population type

Age
Adulthood (19 to 24 years)
Adulthood (25 to 44 years)
Adulthood (45 to 64 years)

Population covered
Sick population

Gender
Male
Woman

Geography area
International

Detail of the geography area
International multicentric cohort (418 centres) involving: 50 COUNTRIES: EUROPE, USA, SOUTH AMERICA, AUSTRALIA and JAPAN

Data collection

Dates

Date of first collection (YYYY or MM/YYYY)
10/1998

Size of the database

Size of the database (number of individuals)
[1000-10 000[individuals

Details of the number of
4724

individuals

Data

Database activity Data collection completed

Type of data collected Declarative data

Declarative data (detail) Paper self-questionnaire

Presence of a biobank No

Health parameters studied Health event/morbidity
Health event/mortality

Procedures

Data collection method Information gathered by another information record: paper questionnaire and on-line (completed by cord blood banks and data managers or transplant centres)

Participant monitoring Yes

Links to administrative sources Yes

Linked administrative sources (detail) EUROCORD DATABASE AND EBMT REGISTER (PROMISE DATABASE)

Promotion and access

Promotion

Link to the document <http://www.ncbi.nlm.nih.gov/pubmed/24986801>

Link to the document <http://www.ncbi.nlm.nih.gov/pubmed/24972767>

Link to the document <http://www.ncbi.nlm.nih.gov/pubmed/24961645>

Link to the document <http://www.ncbi.nlm.nih.gov/pubmed/24946719>

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Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/23247725
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/23242594
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/19796275
Link to the document	http://www.ncbi.nlm.nih.gov/pubmed/22814031
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Access	
Terms of data access (charter for data provision, format of data, availability delay)	Data may be used by academic teams Access determined by the Eurocord Scientific Council, The French Stem Cell Society (sfgm-tc) and EBMT To be determined if data may be used by industrial teams Contractual access with Biotech and pharmaceutical industry in discussion, but not currently active
Access to aggregated data	Access on specific project only
Access to individual data	Access on specific project only