Request to share data between Eurocord and the EBMT registry - INFORMATION

12th July, 2016

Dear Colleague,

The Eurocord registry is an international registry which works in collaboration with EBMT and cord blood banks. The Eurocord registry collects outcome data on cord blood transplants performed worldwide with cord blood units (CBU) released from European cord blood banks, or cord blood transplants performed in EBMT transplant centers with units coming from any cord blood bank worldwide. For more information see:

http://www.agence-biomedecine.fr/Donation-and-transplantation-of

Large European public cord blood banks have signed an agreement for services with the Eurocord registry in order to receive cord blood transplant outcome data on their released cord blood units. In addition, at time of delivery of a cord blood unit to a transplant center, the cord blood bank sends the Eurocord registry a detailed report of the characteristics of that unit and the identification of its intended recipient.

One of the important missions of the Eurocord registry is to collect and validate the necessary cord blood graft data needed for national and international health accreditations.
The EBMT has created a virtual registry for the Eurocord registry which will allow the latter to see the data needed for their processes. This means that, should you so wish, your centre will be able to report to EBMT and to the Eurocord registry while submitting the data only once. In order for the data sharing to take place, it is necessary that you provide the EBMT with a formal request allowing the Eurocord registry to see the data from your centre which is registered in the EBMT database. This you can do by completing and returning the "Permission request form", which you can find in:

https://www.ebmt.org/ebmt/documents/eurocord-request-form-data-sharing-ebmt

Data items essential for Eurocord-ABM registry to provide its service to the cord blood banks are listed at the end of the Permission request form. All of these data is included in the EBMT Med-A and Med-B forms.

With this reporting, your center will contribute to the improvements of cord blood banking in public cord blood banks and our knowledge on cord blood transplants.

IMPORTANT NOTE: It is the responsibility of the centre to ensure that the request conforms to the consent signed by the patient regarding data transmission.

We will be happy to answer any questions you may have regarding this request.

Thanking you for your consideration.

Yours sincerely

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Data that Eurocord - ABM registry will share with the cord blood bank providing the cells

-patient's date of birth

-patient's diagnosis

-patient's status at time of transplant

-patient's HLA typing

-patient's weight at time of transplant

-conditioning regimen with doses of different drugs and/or TBI

-type of cord blood transplant performed (single unit, double unit, co-injection of other hematopoietic stem cells, etc)

-total nucleated and CD34+ cells injected for each cord blood unit, in 10^7/kg and 10^5/kg respectively

-cells viability after thawing in an aliquot or at CBU infusion

-any adverse event associated with the administration of the cord blood unit

-acute GVHD prophylaxis regimen

-presence or absence of acute GVHD, if so: date, grade, treatment

-date of neutrophils recovery >0.5 x 10^9/l

-date of platelets recovery >20 x 10^9/l

- chimaerism during the first 100 days after Treatment, with % of donor. In case of double CBT, chimaerism by CB unit is required. In case of more than one graft product used for administration, which product engrafted.

-date of last follow-up at least 100 days post transplant, with living status (dead or alive)

-cause of death

-if rejection, date and treatment

-if relapse, date and treatment

-if the cord blood unit has not been injected to the recipient: reasons for not injecting the unit